The Management of Feeding Difficulties in Children with Cerebral Palsy in Bangladesh

A thesis submitted for the degree of Doctor of Philosophy

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Declaration

I, Melanie Sara ADAMS

Confirm that the work presented in this thesis is my own.

Where information has been derived from other sources,

I confirm that this has been so indicated in the thesis.

Signature…… Date……

Abstract

The majority of children with Cerebral Palsy (CP) have feeding difficulties, which result in chronic malnutrition and respiratory disease, reducing quality of life for caregiver and child, and causing early child mortality. In well-resourced countries, high and low-tech medical interventions, ranging from gastrostomy tube-feeding to parent training, are available. In Bangladesh the former is not viable and the latter is both scarce and its effectiveness not evaluated.

The study aimed to evaluate the effectiveness of a training programme to improve the feeding practices of carers of children with CP, observing the impact on level of nutritional intake, risk of aspiration and distress caused to both during feeding.

Thirty-seven caregivers and their children aged 1-11 with moderate-severe CP and feeding difficulties were invited to a six-session training programme. Pre and post measures (quantitative and qualitative) were taken during home visits in addition to giving brief advice. A control phase was evaluated for 12 of the participant pairs whilst awaiting training.

A minimum of four training sessions was successful in significantly improving children's nutritional intake and chest health, maximising independence in feeding, improving the experience of mealtimes for both child and caregiver, decreasing caregiver stress regarding their child's feeding difficulties and improving child levels of cooperation. Catch-up growth was observed in 26% of the children. A significant difference in the outcomes between advice only and groups was observed.

In conclusion, carers in Bangladesh, who have minimal formal education and live in abject poverty are able to change care-giving practices significantly after four training sessions, with positive consequences for both child and caregiver. Methods of providing affordable food supplementation need to be investigated and further steps must to be taken to lobby policy-makers in order to ensure that services have the motivation and capacity to address this area of need.

Dedication

I dedicate this thesis to the world's children and carers who are vulnerable, marginalised and ignored because they constitute a minority group struggling to cope with severe disability. I hope that the work for this thesis will help in some way to raise awareness in those who are in a position to do something to change this.

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Abbreviations

BSL	Baseline assessment
BMIZ	Body-mass index *z*-score
CG	Caregiver
CP	Cerebral palsy
EAR	Estimated average requirement
DFID	Department for International Development
GOR	Gastroesophageal reflux
GMFCS	Gross Motor Function Classification System
HAZ	Height-for-age *z*-score
ICDDR,B	Institute for Diarrhoeal Disease Research, Bangladesh
Kcal	Kilocalories
MUAC	Mid-upper arm circumference (raw score)
MUACZ	Mid-upper arm circumference *z*-sore
NGO	Non-governmental organisation
NY	New York state
PAR	Post-advice review
PI	Principal investigator
PTR1	Post-training review 1
PTR2	Post-training review 2
RA	Research assistant
REE	Resting energy expenditure
SD	Standard deviation
SQCP	Spastic quadriplegic cerebral palsy
UCL	University College London
USA	United States of America
UK	United Kingdom
WHO	World Health Organisation
UN	United Nations
UNDP	United Nations development Programme
UNICEF	United Nations Children's Fund
WAZ	Weight-for-age *z*-score
WHZ	Weight-for-height *z*-score

Glossary of Terms

Anthropometric measurements: Measurements of the body, such as weight and length, used for the assessment of growth, nutritional status and other functions.

Appropriate Paper-based Technology: A low cost method of producing objects including furniture, pioneered by Bevill Packer and his Zimbabwian students in the 1970s. The main construction material is a combination of corrugated cardboard and rolls of thin card. Joints are tightly strapped with layered strips of paper. Flour is used to make the paste and varnish, and waterproof paint is often used to seal the completed item. Furniture is made using engineering principles in the design and construction, to ensure its strength.

Enterally: Passing directly into the stomach.

Gastro-oesophageal reflux: A condition where the gastric contents of the stomach return to the oesophagus. Sometimes, gastric contents return to the pharynx and cause regurgitation and vomiting.

Gastrostomy: The surgical formation of an opening through the abdominal wall into the stomach.

Head in extension: Head leaning backwards.

Head in flexion: Head tilting forwards.

Oral sensorimotor therapy: Facial and/or oral massage and exercises targeting the muscles used in eating and drinking.

Pharyngeal stage of eating/drinking: The stage of eating and drinking whereby the ingested material passes through the pharynx and is swallowed.

Stunting: Low weight-for-age in comparison to the reference population median.

Videofluoroscopy: A radiographic study of a person's swallowing mechanism that is recorded on videotape. Videofluoroscopy shows the physiology of the pharynx, the location of the swallowing difficulty, and confirms whether or not food particles or fluids are being aspirated into the airway

Wasting: Low weight-for-height in comparison to the reference population median.

Chapter 1

Introduction

1 Introduction

This chapter summarises the literature which formed the theoretical basis for the study and outlines the key issues for children with cerebral palsy and their caregivers. It presents the rationale for investigating this theme and summarises the outcomes of previous research (from well-resourced and resource-poor countries), outlining the range of possible interventions and their effectiveness. The final section describes the study environment and location.

1.1 Background to the study

The target population for the study is children with moderate-severe cerebral palsy (CP) living in poor circumstances in Bangladesh. These children are at high risk of malnutrition and dehydration due to difficulties with eating and drinking (caused by oromotor impairments), which in turn impacts on their general health and overall development. Feeding difficulties are also the cause of chronic respiratory disease, which is believed to be the predominant cause of death in children with severe CP. If these difficulties are not managed, the child's overall life expectancy is considerably reduced. Difficulties with feeding understandably have an effect not only on the children's quality of life but also on that of their caregivers and family.

The United Nations (UN) convention on the Rights of the Child (1989) states that ***"…a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community"*** (Article 23, paragraph 1). It also says that, "State parties (shall) recognise ***the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health*** …. *(*and) ***shall strive to ensure that no child is deprived of his or her right of access to such health care services"*** (Article 24, paragraph 1). Key principles emphasized in the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) include respect for ***dignity, choice, equality of opportunity, evolving capacities*** and ***accessibility.***

In order for children with cerebral palsy and feeding difficulties to live a ***full and decent life with dignity, maximum self-reliance and active participation in the community,*** they require adequate support from responsive caregivers (who are informed and well-supported themselves) and the availability of services and facilities that are able to meet their needs and those of their caregivers. In most high-income countries, a variety of inpatient, outpatient and community-based services exist for this

population, including high cost, high-tech invasive medical procedures a well as low tech solutions involving caregiver training. Despite this, and the years of investigation into this subject, researchers have commented on the surprisingly little attention this population has received from health services, even in well-resourced parts of the world (Dahl *et al*., 1996; Motion *et al*., 2002; Sullivan *et al.*, 2000). The nutritional needs of two-thirds of the children enrolled in a large population-based study in Oxford (UK) (Sullivan *et al.*, 2000) had never been assessed. Samson-Fang *et al.* (2002) believe that added to this, is the resistance some families may feel to investing in the prevention of, or treatment for malnutrition as it involves extensive time and effort on the part of the family and child, and alternative feeding options may be deemed undesirable. Mallory *et al.* (1993 cited in Yousafzai *et al*., 2003c) also believe that disabled children living in poverty may be particularly at risk of inadequate nutritional status, due to financial constraints or social beliefs. Families with disabled children are reported to be amongst the poorest, suffering additional costs associated with medication and health care, rehabilitation, special equipment and transport costs. Furthermore, the additional care burden impacts on the possibilities for employment of the main caregiver (Dobson and Middleton, 1998).

In Bangladesh, even fewer services exist for this population and their caregivers. Nutritional projects and services for children with malnutrition are commonplace, however access to these projects is either denied or not actively facilitated for children with disabilities. Some health professionals, working in national hospitals and centres for the disabled, offer basic nutrition and feeding advice to caregivers, but the services are limited and their effectiveness questionable. Effective and affordable nutritional and feeding interventions are of even greater importance however, in a low-income country with widespread malnutrition even amongst the non-disabled population. Researchers from the Centre for International Health and Development (UCL Institute of Child Health) have investigated the nutritional status of disabled children in Nigeria (Thompsett *et al.,* 1999), The Philippines (Socrates *et al.,* 2000) and India (Yousafzai *et al*., 2003a, 2003c). These studies identified that children with CP were significantly less nourished than their counterparts in the West and also scored significantly below their siblings and neighbours in weight and height. They related these problems to feeding difficulties and concluded that there was an urgent need to address these issues.

Without intervention, the child's ***dignity*** is at risk through disrespectful and abusive caregiver feeding practices resulting from caregiver stress during feeding (Hurley *et al.* (2008). Their ability to make ***choices*** about when, what and how much they want to

eat is compromised by their physical and communication difficulties (Reilly and Skuse, 1992). Optimum health is prevented by malnutrition, dehydration and the aspiration of food stuffs during feeding (Sullivan *et al.*, 2000). Ill-health in turn impacts on the child's ability to evolve to their maximum ***capability***, ***participate in community life*** (Samson-Fang *et al.*, 2002) and therefore further limits their ability to achieve ***equality of opportunity*** and ***access.*** Children with disabilities are often excluded from mainstream healthcare and nutrition services for various reasons, most of which are caused by lack of education and training on the part of the caregiver as well as the service providers.

Recommended methods by the UN for ensuring these rights are upheld include ***"…diminish(ing) infant and child mortality…combat(ing) disease*** *and* ***malnutrition****,* ***within the framework of primary health care****, through…..the application of* ***readily available technology*** *and through the provision of* ***adequate nutritious foods…*** *To ensure that all segments of society, in particular* ***parents*** *and children,* ***are informed****, have* ***access to education*** *and* ***are supported in the use of basic knowledge of child health and nutrition****…"*

The UN also promotes, "…***in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries".*** (Article 23, paragraph 4).

The need to design an intervention appropriate for children with cerebral palsy and feeding difficulties living in resource-poor environments and build the capacities and skills of their health workers and caregivers was therefore clear. Such an intervention would need to address issues of mortality, morbidity, adequate nutrition, dignity, choice, independence and independence using readily available technology.

1.2 Cerebral Palsy

Cerebral Palsy (CP) is an umbrella term used to describe a group of non-progressive motor impairment syndromes caused by lesions or anomalies of the developing brain, arising before, during or after birth. These syndromes are characterised by the dysfunction of movement, posture and muscle tone. Cerebral palsy is usually accompanied by sensory deficits, learning disabilities, behavioural disorders and seizures (Del Giudice, 1997; Stanley *et al*., 2000). The likelihood and severity of associated disabilities increases with the increasing severity of the motor impairment (Stanley *et al*., 2000). The degree of independence in activities of daily living is determined by the severity of the impairments, the amount of rehabilitation the child has / is receiving and the way in which the child is supported by their caregiver. The load on the caregiver likewise depends on the first two factors.

Cerebral palsy is usually classified using clinical descriptions of the type of muscle tone, bodily distribution and severity of the motor impairment. The most commonly used categories to describe type are spastic, athetoid, dystonic and hypotonic; the first being the most common. In terms of topography, the four commonly occurring distributions of cerebral palsy are quadriplegia, depicting the involvement of all limbs; diplegia, which describes the involvement of the lower limbs predominantly; and left/right hemiplegia, where one side of the body only is affected, with the upper limb usually more affected than the lower. In its mild presentation, an individual with Cerebral Palsy will be fully independent, in contrast to an individual with severe CP, who will be dependent on others for all aspects of daily living.

Global figures state that 2-2.5 in every 1000 children are born with CP, with additional numbers developing the condition in the early years of life (Stanley *et al*., 2000). Risk factors pertaining to situations of poverty, such as low birth-weight, can increase this figure to as much as 50-60 per 1000 infants (Sullivan *et al.*, 2000). Although national statistics regarding children with cerebral palsy are not available, a study by Khan and Durkin (1995 cited in Mobarak *et al*., 2000) predicts the prevalence rates of children in Bangladesh with severe disability at 22 per 1000, although this does not distinguish the type of disability. An international epidemiological study carried out in 1987-88 to develop a screening tool for childhood disability produced estimated prevalence rates of motor disabilities (in Bangladeshi children aged 2 to 9 years) of 5.62 (urban) and 6.49 (rural) per 1000 (Zaman, 1990 cited in Zaman, 1994), however, the type and severity of the disorder was again not specified. In a study designed to identify the probable causes of CP in Bangladesh, 1.72% of the 6412 patients who attended the Department of Physical Medicine at the Bangabandhu Sheikh Mujib Medical University

Hospital during the 9 month study period, were diagnosed with cerebral palsy. The most common causes of spastic quadriplegia were neonatal convulsion, jaundice and birth asphyxia. Causes of the remaining types of CP included prematurity, neonatal convulsion, neonatal infection and trauma. Early motherhood, maternal malnutrition, the predominance of pre-term and underweight births, widespread infection and the high risk of birth trauma all contribute to the occurrence of CP in Bangladesh.

The inextricable link between poverty and disability is illustrated in Figure 1.1 below and amplified by writers such as Helander (1992) and Elwin (1999). It should be recognised however that it is not only the individual with disabilities who is disadvantaged economically but the rest of the family, due to additional costs referred to above (p18).

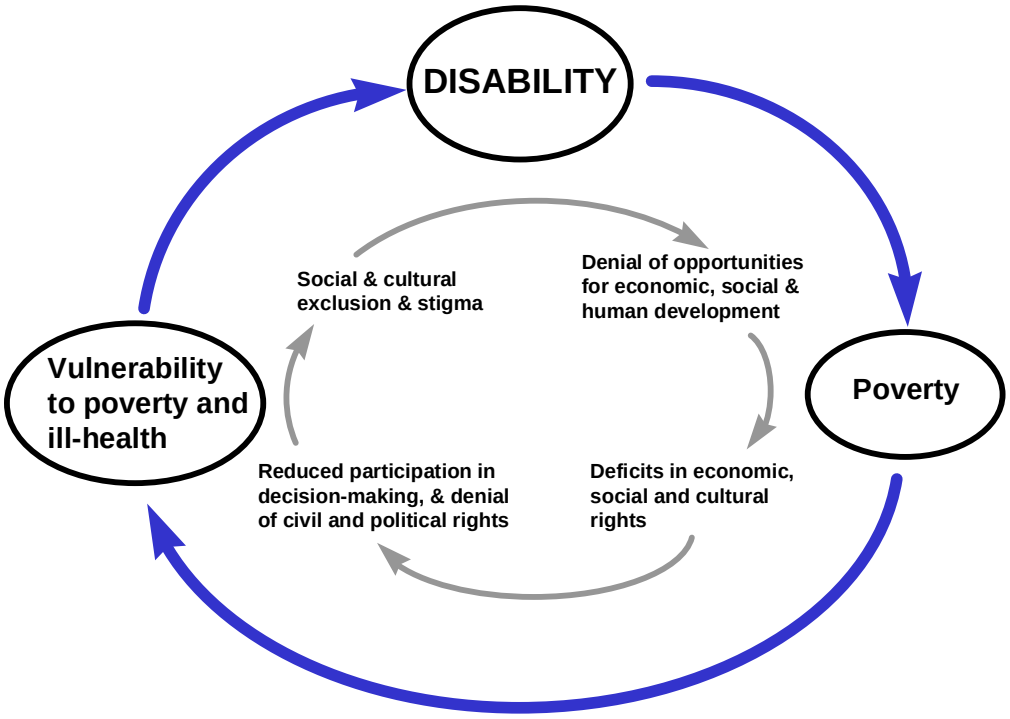


Figure 1.1 Poverty and Disability - a vicious cycle

Disability, Poverty and Development, February 2000, Issue paper, DFID.

Children with CP are known to suffer from a variety of health complaints. In a multi-centre population-based cross-sectional survey carried out in the USA on 235 children aged 2-18 years with moderate to severe impairment, the CP children scored significantly below the mean on the Child Health Questionnaire (CHQ) (Landgraf and Ware, 2006) for pain, general health and physical functioning (Liptak *et al.,* 2001; Fung *et al*., 2002). Poor health in this population was also reflected in their higher use of

medications and health services and their high levels of absenteeism from school and other usual activities. The children with the greatest degree of physical disability and who required alternative feeding, required the most health care resources, used the most medications, had the most respiratory problems and had the lowest Global Health scores. Managing the chronic health problems of their child, in addition to the demands of everyday living, is one of the main challenges for parents (Raina *et al*., 2005).

1.3 CP, growth and malnutrition

Children with CP have been reported to suffer from growth disorders since the 1960's (Shapiro *et al*., 1986). In a recent study to develop a growth chart for children with spastic quadriplegic CP (SQCP) involving 360 North American children, Krick *et al*. (1996) found that the median weight and height of these children were between -2 and -2.5 *z*-scores below the national average, using the National Center for Health and Statistics (NCHS) growth standards (Hamill *et al*., 1979), even though 50% were receiving nutritional therapy. In a cross-sectional survey of 171 children, Stevenson and colleagues (Stevenson *et al*., 1994) found that linear growth correlated negatively with age with older children diverging more greatly from the norm.

Although non-nutritional reasons for the growth differences between CP and non-CP individuals, such as dysregulation of growth hormone secretion and muscle spasticity have been identified (Strodel, 1987; Coniglio *et al*., 1994; Stevenson *et al*., 1995; Krick *et al*., 1996), it is largely believed that a combination of these factors together with malnutrition is responsible for the differences (Shapiro *et al.*, 1986; Stallings *et al*., 1993b, 1995; Stevenson *et al*., 1994).

Understandably, researchers have been keen to identify the significance of the nutritional element to the growth failure observed, in order to understand whether nutritional therapy is indeed required in this population. Signs of malnutrition are evident in the growth patterns and estimated energy intake of children with CP, with muscle store depletion and linear growth failure mirroring those deficits found in individuals suffering from chronic malnutrition (Stallings *et al.,* 1993b). From a study comparing the dietary intake, anthropometric measurements and energy expenditure between a group of children with SQCP (*N*=61) aged 2-18 years, and non-disabled controls (*N*=37), Stallings *et al.* (1996) concluded that the commonly found low resting energy expenditure levels (measured through indirect calorimetry) and low fat stores are result of the body's adaptation to chronically low food intake.

In a population-based survey targeted at children with disabilities in the Oxford area of the UK (Sullivan *et al.*, 2002), information from 41 caregivers revealed that only 20% of their children with neurological impairments were regularly achieving over 100% of their estimated average requirement (EAR) for energy intake, with 59% of the children with more severe disabilities consuming below 80% EAR. Micronutrient levels were less markedly impaired, though only 46% achieved reference nutrient intake levels for iron (which is especially important for neuro-developmental progress). Micronutrient deficiencies are likely to be more marked in children with CP in developing countries

however, where malnutrition caused by poor quality diet is common even in the general population. In the Indian slum study by Yousafzai *et al.* (2003), the children with disabilities had significantly low haemoglobin levels resulting in a 78% prevalence of anaemia and showed a 35% prevalence rate of vitamin A and D deficiency.

In the study by Samson-Fang *et al.* (2002), the results showed that 47% of their study children (moderate-severe CP) weighed below the 5th percentile (ie. below -1.65z-scores) for their age and gender, and performed poorly on all areas of anthropometric measurement. Low fat stores, decreased muscle mass and stunting were found in a large percentage of the children, indicative of both acute and chronic malnutrition.

A significant relationship between gross motor function, growth and nutritional status has been observed (Thommessen, 1991c; Dahl *et al*., 1996; Samson-Fang *et al.,* 2002; Sullivan *et al*., 2002). It therefore follows that those types of CP which impact most on motor functioning are associated with a greater nutritional risk, and that most research studies have focussed on children with spastic quadriplegic CP.

The majority of studies investigating the nutritional status of children with disabilities have also been conducted in high-income countries. However, the results from countries with widespread malnutrition in the general population (Tompsett *et al*., 1999; Socrates *et al.*, 2000; Yousafzai *et al*., 2003a) show us the heightened risks to children in these environments. A study carried out in Bangladesh by Rayhan and Khan (2006), using information from a national survey, revealed that 45% of the children under the age of five were suffering from chronic malnutrition, 10.5% were acutely malnourished and 48% had an ‘underweight problem’.

The following table summarises the key studies exploring the relationship between Cerebral Palsy and malnutrition.

Table 1-1 Studies from high-income countries

Authors & location	Study aim	Participants	Methods	Outcome
Stallings *et al.* (1993b) USA	Test the hypothesis that poor nutritional status, as indicated by depleted subcutaneous fat stores & muscle stores is an identifiable cause of growth failure in children with SQCP (Spastic Quadriplegia).	*N*=142. SQCP. 2-18 years. From 3 tertiary centres	Anthropometrics (muscle area & % body fat – used to evaluate nutritional status), Assessment of CP, feeding assessment based on parental interview – scored 1-5 severity based on presence of specific of oromotor features.	Clinically significant malnutrition was present even at 2 years of age. Association between nutritional status & severity of CP (oromotor score & ambulation) – especially in older children. Disease severity variables explained 70-75% and nutritional status explained 10-15% of linear growth variation. Nutritional status – greater effect on linear growth in younger children. Oromotor skills had more significant association with growth in the older children. Growth characteristics of CP are similar to chronic malnutrition. ie. decreased muscle stores & linear growth.
Stallings *et al*. (1996) USA	Compare dietary intake, growth measures & energy expenditure of children with CP and non-disabled controls.	*N*=61 SQCP. 2-18 years. From 2 university-based tertiary care centres. Controls N=37.	Reported dietary intake (3-day records), anthropometrics and indirect calorimetry.	Values for all measures of nutritional status in SQCP group were significantly lower than controls. Resting energy expenditure (REE) was significantly different between SQCP with low fat stores and controls, but not between adequate fat stores and controls. Feeding score significant and negatively related to REE. SQCP with low fat stores, significantly lower reported daily energy intake than controls. Adequate fat stores - no significant difference. Conclusion: Low REE levels & low fat stores are result of body's adaptation to chronically low food intake.

Authors & location	Study aim	Participants	Methods	Outcome
Krick *et al*. (1996) USA	Provide a growth reference standard for children with SQCP.	*N*= 360. SQCP. 0-120 months. 50% partially or wholly tube-fed	1,630 observations. Measurements taken during outpatient visits & from retrospective review of charts.	Boys Girls HAZ[1]: -2.3 -2.1 WAZ[2]: -2.4 -2.1 WHZ[3]: -1.3 -1.1
Samson-Fang *et al.* (2002) USA	Describe the nutritional status of a population-based sample of children with mod-severe CP. Explore relationship between nutritional status, health & functional outcomes	*N*=235 Mod-severe CP. 2-18 years. Population-based strategy used to enrol children from 6 geographical areas.	Anthropometrics, determined severity of motor impairment, two caregiver interviews including the Child Health Questionnaire.	Malnutrition was common in mod & severe CP. 47% weight below 5th percentile for age & gender. Low on all anthropometric measures. Significant relationship between severity of gross motor function & nutritional status. Malnutrition was associated with poorer health status & limitations on societal participation. 42% of those with most severe motor impairments were fed via gastrostomy.

[1] Height-for-age *z-score*
[2] Weight-for-age *z*-score
[3] Weight-for-height *z*-score

Table 1-2 Studies from low-income countries

Authors & location	Aim	Subjects	Methods	Outcome
Tompsett *et al.* (1999) NIGERIA	Compare the nutritional status of disabled children with their non-disabled siblings and neighbours in Nigeria. Investigate appropriate anthropometric techniques for this population and situation.	*N*=122 children with various disabilities. <10 years. Sibling (*n*=87) and neighbour (*n*=112) controls.	Assessment of anthropometry and haemoglobin levels.	Mean WAZ (-1.6) and HAZ (-2.5) significantly lower than siblings (-1.1; -1.8) and neighbours (-1.0;-1.3). WHZ and MUAC[4] near normal for all groups. Haemoglobin levels of disabled children not affected.
Socrates *et al*. (2000) PHILIPPINES	Compare nutritional status of children with CP with siblings & neighbours. Compare the siblings with neighbours. Examine relationship between feeding difficulties & the severity of CP, & nutritional status.	*N*=31. CP (14 severe, 12 mod, 5 mild). 2-10 years. Identified through local health services. Siblings (*n*=20), control group of neighbourhood children (*n*=64).	Compared with siblings & neighbourhood children matched for age and sex. Anthropometrics- weight, height, armspan.	Significantly (at least 1.5 z-scores) more wasted, stunted & underweight than siblings & neighbourhood children. Significantly lower growth scores (at least 1.5 z-scores less) than SQCP in USA in WH, HA, WA. Significant association between severity of feeding or CP & WA.
Yousafzai *et al.* (2003a) INDIA	Explore the nature, extent & probable causes of nutritional deficiencies among children with disabilities living in a slum in India.	*N*=141 children with disabilities. 2-6 yrs. Sibling (*n*=122) & neighbour (*n*=162) controls.	Information on food patterns, anthropometric assessment, micronutrient status, reported feeding difficulties.	Mean WAZ of disabled children (-2.44) was significantly lower than sibling (-1.7) and neighbour (-1.83). Disabled children had significantly lower Haemoglobin levels. Children with feeding difficulties were significantly more likely to be malnourished (WA, HA, WH).

[4] Mid-upper-arm circumference

1.4 Effects of malnutrition

Malnutrition in non-disabled populations has been seen to have adverse effects on individuals' muscular, respiratory, cardiac and immune systems (Walker *et al.*, 1991; Pelletier 1994; Laaban, 1997) as well as cognitive and motor development (Walker *et al.*, 1991; Grantham-McGregor and Fernald, 1997). Furthermore, studies have shown that when associated with poverty and poor levels of stimulation in the home, the effect of malnutrition on the child's cognitive development is greater (Simeon and Grantham-McGregor, 1989 cited in Socrates *et al*., 1997).

A strong relationship between nutrition and infection is widely recognised amongst health researchers. In this relationship, malnutrition adversely affects a person's ability to resist and/or respond to infection, and infection adversely affects a person's ability to utilize energy and nutrients obtained from their diet (Briscoe, 1979; Pelletier, 1994). Briscoe (1979) estimated that in a cohort of non-disabled Bangladeshi children aged <5 years, 9% of their food was not used for maintenance, growth or activity and that this figure could be reduced to 3% if all sources of infection were eliminated. Pelletier (1994) reviewed of a series of community-based studies conducted in developing countries, and observed an inverse relationship between nutritional status and mortality, which is greater in severe malnourishment (<60% weight-for-age (WA)) but nonetheless significant in children with moderate (60-69% WA) and mild (70-79% WA) malnutrition. Furthermore, the degree of vulnerability to disease was seen to be proportional to the severity of malnutrition. He concluded that, by applying the results of eight epidemiological studies of malnutrition and mortality, to a larger set of 53 countries, it could be said that an average of 56% of all child deaths are due to the potentiating effects of malnutrition on disease, of which 83% are due to moderate-mild malnutrition.

The specific effects of malnutrition on the health of children with CP have also been investigated. In studies by Samson-Fang *et al.* (2002) and Stevenson *et al*. (2006), low energy stores were significantly related to increased healthcare and decreased social participation. As with the non-disabled population, studies show an increased risk of infection (Tomkins and Watson, 1989; Khan *et al*., 1998), especially in the respiratory and urinary tracts (Sullivan *et al*., 2000). Malnutrition impairs muscle strength, which not only affects overall mobility, but compromises respiratory health, which is one of the main risk factors for early mortality in this group of children (Strauss *et al.*, 1998; Reddihough *et al*., 2001) by reducing the strength of the cough reflex and thereby increasing the individual's vulnerability to aspiration pneumonia (Russell *et al.,* 1983; Efthimiou *et al*., 1988). The risk of chest infection is further impacted on by the

association between malnourishment and a higher incidence of gastroesophageal reflux (GOR) (Lewis *et al.,* 1994). Khan *et al*. (1998), in their study on 92 Bangladeshi children aged 1;4 to 5;7 found that malnutrition in association with severity of disability, was linked to early mortality. (Other factors included caregiver education level and poverty).

Improved nutrition can lead to the healing of persistent pressure sores and the correction of cold and cyanosed extremities (Patrick *et al.*, 1986). Likewise, levels of spasticity appear to be reduced, which may impact on oromotor functioning (Gisel and Patrick, 1988) thereby improving feeding ability, and may help to explain the results of the study by Lewis *et al*. (1994) whereby nutritional rehabilitation was associated with the resolution of gastro-oesophageal reflux in six out of the ten children studied.

With the recognised effects of chronic malnutrition on overall health, physical and cerebral functioning, coupled with increased irritability and decreased motivation and energy for non-essential activities such as rehabilitation (Stallings *et al.*, 1993b), malnutrition not only affects these children's general well-being (Patrick *et al.*, 1986), but is likely to have negative consequences both on the degree of disability (Sullivan *et al.*, 2000) as well as aspects of societal participation, such as school attendance and regular activities (Samson-Fang *et al.*, 2002).

1.5 CP, feeding difficulties and malnutrition

1.5.1 Feeding difficulties in CP

Feeding difficulties in children with CP have been identified as a major factor associated with both growth failure and nutritional deficits (Shapiro *et al.*, 1986, Gisel and Patrick, 1988; Thommessen *et al.*, 1991a, 1991b, 1991c; Stallings *et al*., 1993a, 1993b, 1996; Dhal *et al.*, 1996; Troughton and Hill*,* 2001; Fung *et al*., 2002) and have been cited as one of the most powerful prognostic factors for survival (Eyman *et al*., 1990 cited in Sullivan and Rosenbloom, 1996; Strauss *et al*., 1998; Reddihough *et al.*, 2001). Despite the fact that many studies not only identify the co-existence of malnutrition and feeding difficulties, but also observe associations between degree of feeding disability and the level of malnutrition, some researchers have remained sceptical of a causal link between the two, suggesting that poor growth and undernutrition may rather be due to unusually high energy needs in children with spasticity or athetosis, leading to inadequate nutritional levels being achieved (Shapiro *et al*., 1986; Dahl *et al*., 1996). Stallings *et al*., (1996) showed however, that energy requirements for the 61 children with SQCP in their study were reduced in all areas (resting energy expenditure, physical activity, total energy expenditure) and far less than those required for non-disabled children of a similar size. Similarly, Azcue & Zello (1996) found that a group of 13 children with SQCP had significantly lower energy requirements than their non-disabled counterparts.

In 2001, Troughton and Hill investigated the relationship between feeding difficulties and nutritional status using an objective feeding assessment tool. The ability to self-feed was assessed through parental questioning and clinical examination, and oromotor feeding competence was assessed using a modified version of The Multidisciplinary Feeding Profile (Kenny *et al*., 1989; Gisel *et al*., 1995) in which oromotor skills were evaluated on specific feeding tasks. The results showed that the children in the study who were undernourished had lower feeding competence scores. This mirrored the results of an earlier study by Griggs and colleagues (1989 cited in Gisel *et al*., 1995) who found a direct association between severity of oral and pharyngeal feeding difficulties as identified through videofluoroscopy, and weight-for-age.

Fung *et al.* (2002), who studied 230 children with moderate-severe CP in the USA and Canada, found that even those with mild feeding dysfunction had a mean WAZ of -2.5 in comparison to those without feeding dysfunction who had a mean WAZ of -1.7, and those with moderate feeding dysfunction had a mean WAZ of -3.3 (based on the

National Centre for Health and Statistics Percentiles, Hamill *et al*., 1979). Similar scores for stunting were observed and a strong correlation was found between severity of feeding dysfunction and poor health, in addition to growth failure and malnutrition.

The following table summarises studies exploring the relationship between feeding difficulties and malnutrition.

Table 1-3 Studies from high-income countries

Authors & location	Study aim	Participants	Methods	Outcome
Gisel & Patrick (1988) CANADA	Identification of children with CP unable to maintain a normal nutritional state using assessment of eating efficiency.	*N*=7. Severe CP & growth failure. 1-16 years.	Compare eating efficiency of a group of children with severe CP and non-disabled controls of same weight. Two different textures, time to eat 10 bites,	Children with CP took 2-12 times longer. Even long mealtimes did not compensate for the severity of the feeding impairment.
Thommessen *et al.* (1991a) NORWAY	Explore the prevalence of growth retardation & feeding problems in a sample of children classified into 7 diagnostic groups. (Feeding problems: self-feeding, oral-motor dysfunction, lack of appetite, food aversion)	*N*=221. Disabled children, 35 with CP. 1-16 years. Children attending tertiary centre.	Retrospective records on growth and cross-sectional data on growth outcomes.	Presence of mechanical feeding difficulty associated with severity of disability. Height & weight significantly lower in those with impaired self-feeding & oral-motor dysfunction.
Thommessen *et al.* (1991b)	Explore the effect of feeding problems / being fed through alternative means, on the energy & nutrient intake of disabled children	*N*=221. Disabled children, 35 with CP. 1-16 years. Children attending tertiary centre	Retrospective records on growth and cross-sectional data on growth outcomes.	Lower energy & nutrient intakes in those with feeding problems than children without. Most significant factors: oral motor impairments and prolonged mealtimes.
Dahl *et al.*(1996) SWEDEN	Study the prevalence & characteristics of feeding difficulties, the problems of growth retardation & malnutrition and the risk factors for undernutrition in children with mod or severe CP.	*N*=35. CP. 2.4-15.2 years (median 8 years) From 2 paediatric rehabilitation units	Parental interviews, medical records, medical assessment & anthropometry.	60% reported by parents to have feeding difficulties. 43% undernourished. Undernutrition significantly associated with severity of disability, tetraplegia, child <8yrs, presence of current or past feeding probs. Feeding problems associated with level of severity of disability & epilepsy, dystonia, growth retardation, poor communication & hand function

Authors & location	Study aim	Participants	Methods	Outcome
Troughton & Hill (2001) N. IRELAND	Investigate the prevalence of undernutrition in children with CP & determine the relationship with feeding ability.	*N*=90. CP. 2.6years – 18.7 (mean 10.8 yrs). From special schools.	Feeding abilities assessed using Kenny's Multidisciplinary Feeding Profile. Parental questioning & modified version of the Multidisciplinary Feeding Profile (Kenny et al. 1989).	46% undernourished. Lower feeding scores in all aspects of feeding correlated with lack of nutrition ($p<0.002$). Chewing was most significantly correlated skill with growth measures. Undernutrition was common and associated with poorer feeding skills.
Fung *et al*. (2002) USA &CANADA	Describe parent-reported feeding dysfunction & its association with health & nutritional status in children with CP.	*N*=230. Moderate-severe CP. 9.7 years (+/-4.6 yrs). From 6 tertiary centres.	Anthropometry & Child Health Questionnaire & rating scale for severity of feeding problem.	Strong correlation between feeding dysfunction & poor health and nutritional status. Mean WAZ: No feeding dysfunction -1.7 Mild -2.5 Mod -3.3
Sullivan *et al*. (2002) UK	Assess impact of feeding difficulties on the quality & quantity of their diet & their growth.	*N*=100 neurologically impaired with motor or feeding problems (CP *n*=90). 9 years (+/- 2yrs 5 ms) = Subgroup of 271 families selected from regional register of children with early childhood impairments	Caregiver interview, anthropometric measurements & dietetic assessment.	Only 20% achieved energy intakes above the estimated average requirement (EAR) for their age. 59% of children with more severe disabilities consumed below 80% EAR for energy intake. Some impairment in micronutrient levels. Only 46% achieved reference nutrient intake levels for iron.

Table 1-4 Studies from low-income countries

Authors & location	Study aim	Participants	Methods	Outcome
Yousafzai *et al.* (2003a) INDIA (As above, p10)	Explore the nature, extent & probable causes of nutritional deficiencies among children with disabilities living in a slum in India.	*N*=141 children with disabilities. 2-6 yrs. Sibling (*n*=122) & neighbour (*n*=162) controls.	Information on food patterns, anthropometric assessment, micronutrient status, reported feeding difficulties.	Mean WAZ of disabled children (-2.44) was significantly lower than sibling (-1.7) and neighbour (-1.83). Disabled children had significantly lower Haemoglobin levels. Children with feeding difficulties were significantly more likely to be malnourished (WA, HA, WH).
Socrates *et al.* (1997) PHILIPPINES (as above, p10)	Compare nutritional status of children with CP with siblings & neighbours. Compare the siblings with neighbours. Examine relationship between feeding difficulties & the severity of CP, & nutritional status.	*N*=31. CP (14 severe, 12 mod, 5 mild). 2-10 years. Identified through local health services. Siblings (*n*=20), control group of neighbourhood children (*n*=64).	Compared with siblings & neighbourhood children matched for age and sex. Anthropometrics- weight, height, armspan.	Significantly (at least 1.5 z-scores) more wasted, stunted & underweight than siblings & neighbourhood children. Significantly lower growth scores (at least 1.5 z-scores less) than SQCP in USA in WH, HA, WA. Significant association between severity of feeding or CP & WA.

1.5.2 Feeding difficulties: more detail

'Feeding' is a complex activity which is divided by clinicians into five phases. The first is the *pre-oral phase*, which involves getting food/drink to the mouth and therefore necessitates the appropriate gross motor skills for this. This is followed by the *oral phase,* which involves manipulating food/drink in the mouth and pushing it back ready to be swallowed, therefore requiring adequate lip closure, tongue and jaw movement. The *pharyngeal phase*, or the 'swallow', involves a series of mechanical adjustments triggered by sensory stimuli to ensure that the airway and nasal cavities are protected and that food/drink passes into the oesophagus without being aspirated or nasally regurgitated. The *oesophageal phase* refers the food/drink moving down through the cardiac sphincter into the stomach. Feeding therefore requires a complex combination of sensory and motor abilities and is consequently affected by impairments in this area. Swallowing itself necessitates the use of 31 pairs of striated muscles and is susceptible to problems at all levels of the central nervous system.

The term 'feeding difficulties' is normally used to refer to disturbances in eating and drinking attributable to physical, (motor and sensory) and/or behavioural causes. Babbit *et al*. (1994 cited in Southall and Schwartz, 2000, p.V) define feeding problems as 'characterised by an inability or refusal to eat certain food due to physiological and/or psychosocial factors'. Difficulties with chewing or swallowing are often encapsulated in the term 'dysphagia', however definitions for this term vary. The UK National Health Service (NHS direct, 2009) defines the term as any problem arising in the transition of food or drink from the mouth, through the throat, the oesophagus and into the stomach. Some researchers use the term in very specific ways. For example, Sullivan *et al.* (2000) use the term to describe the inability to eat or swallow lumpy food. The term dysphagia is however often used to refer to specific difficulties at the swallow, or 'pharyngeal' stage of eating and drinking. The definition of feeding difficulties in this study encompasses all barriers to effective and sufficient nutrition and fluid intake, which are related to the child's disability. These may involve caregiver behaviours and/or those of the child. In the literature, feeding difficulties refer mostly to a child's ability to feed itself, and the effective management of food in the mouth and during the swallow. The terms oral motor or oromotor function and dysfunction apply to motor skills required in the oral management of food. Eating efficiency, as described by Gisel and Alphonce (1995), is used to mean the ability to 'ingest a nutritionally adequate diet and consume enough calories within a reasonable amount of time to permit growth within normal limits'.

Prevalence figures on children with Cerebral Palsy who have feeding difficulties range from between 40% and 90% (Gisel and Patrick, 1988; Stallings *et al*., 1996; Trier and Thomas, 1998; Reilly *et al*., 1996). This rather broad figure may be accounted for by the differences of interpretation and lack of specificity amongst researchers with regards to the term 'feeding difficulties', small sample sizes and the varying levels of severity of disability in the populations studied.

Reilly *et al.* (1996) however, used standardised assessment procedures in their study to determine the prevalence and nature of feeding difficulties and oromotor dysfunction among a sample of 49 children with Cerebral Palsy (12 to 72 months of age). Their study identified 90% of the children as having clinically significant oromotor dysfunction. Individuals with spastic quadriplegia are reported to experience the greatest difficulty, with up to 85% of these children having severe feeding difficulties (Stallings *et al.*, 1993a; Reilly *et al*., 1996; Troughton and Hill, 2001). Studies also show that the greater the degree of overall motor impairment, the greater the likelihood of feeding difficulties (Dahl *et al*., 1996; Thommessen *et al*., 1991a ,1991c) and the greater the level of feeding difficulty (Fomon *et al.,* 1982 cited in Sullivan *et al*., 2000; Waterman *et al.,* 1992; Samson-Fang *et al.*, 2002).

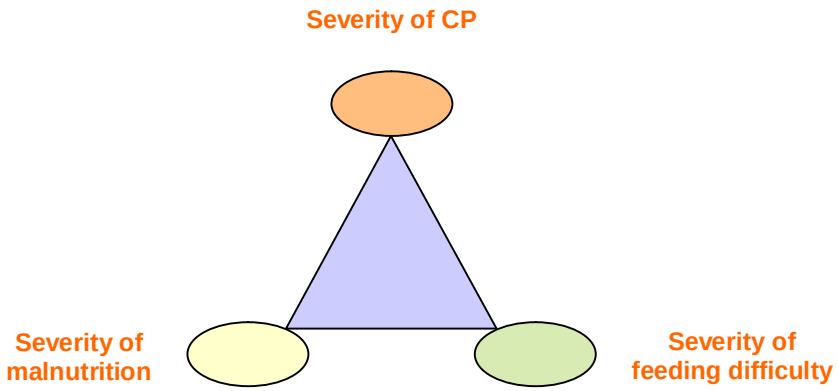


Figure 1.2 The relationship between CP, feeding difficulties and malnutrition

Children with CP can have difficulties at all stages of eating and drinking. The most commonly reported problems in the literature include difficulties with self-feeding, chewing and swallowing (Suzuki *et al*., 1991; Field *et al.,* 2003; Sullivan *et al.,* 2000). Other issues outlined by Reilly *et al.* (1995) include food refusal, lack of initiation to take food offered, problems with biting and sucking, drooling, food/fluid loss during feeding, and sequencing and rhythmicity difficulties.

Researchers have investigated the impact of specific aspects of feeding impairment. The ability to self-feed for example, has been identified as a significant independent predictor of undernutrition (Dahl *et al*., 1996; Vik *et al*., 2001). Oral motor difficulties have been researched in detail, including the impact of specific oral motor impairments such as abnormal tongue thrust, increased or decreased gag reflexes, oral hypersensitivity, bite reflexes and lingual and labial dysfunction, on the oral management of food and drink (Mueller, 1975 cited in Waterman *et al*., 1992; Love, 1980; Helfrich-Miller, 1986; Yokochi,1996). Researchers have even isolated the specific motor skills deficits that impair chewing ability (Gisel, *et al.,* 2000), which was found to be particularly strongly correlated with anthropometric measures associated with wasting (Troughton and Hill, 2001). Oral motor deficits are considered to contribute to inadequate energy intake through food loss caused by oral spillage (Troughton and Hill, 2001), and through diets being predominantly dairy-based, as the more energy dense, nutritious foods are difficult to manage orally (Sullivan *et al.*, 2002). They also prevent adequate intake due to the often unacceptable amount of time and effort required for feeding to satiety (Johnson and Deitz, 1985; Gisel and Patrick, 1988; Sullivan *et al.*, 2000; Troughton and Hill, 2001) with CP children taking up to 15 times longer to eat a mouthful of food than their non-disabled counterparts resulting in some parents spending over 7 1/2 hours a day in feeding (Johnson and Deitz, 1985). Indeed, Sullivan *et al*. (2000) suggest that the length of time required for feeding can be used as a reliable measure of severity of feeding impairment and therefore indicator of need for supplementary feeding. Reilly *et al.* (1996), however, found that the duration of mealtimes of the children with significant oral motor dysfunction in their study did not differ significantly from that of the matched comparison group and that they were in fact relatively brief, with length of mealtime being inversely proportional to the severity of the oral motor deficits. Yousafzai *et al*., (2003a) found similar results in their study in India, and shorter mealtimes were identified as a risk factor for malnutrition in this group by Hung *et al.* (2003). It would seem that in many cases, extra time is not in fact given to compensate for the feeding difficulty and as a result, the children are additionally disadvantaged. When observed in a more controlled fashion however, Gisel and Patrick (1988) suggest that eating efficiency provides a good basis for early identification of children who will need nutritional therapy via non-oral means, in order to achieve adequate nourishment.

Apart from these physical difficulties mitigating adequate oral intake, children with disabilities have an apparent lack of appetite and thirst compared with siblings (Gisel and Patrick, 1988; Suzuki *et al*., 1991; Yousafzai *et al.*, 2003a, 2003c). Trier and Thomas (1998) suggest that a lack of appetite, as perceived by caregivers, may be

caused by recurrent chest infections or urinary tract infections and a learned aversion to food, arising from previous unpleasant feeding experiences secondary to coughing, choking, aspiration during feeding, force-feeding or painful oesophagitis. Another factor affecting appetite may be bodily pain, which is common in this population and all the more so in children with a greater degree of disability (Houlihan *et al.,* 2004). GOR, which is present in up to 75% of children with CP (Booth, 1992) has been identified as a significant factor contributing to food refusal and lack of appetite (Field *et al.*, 2003), as has constipation, present in up to 59% (Sullivan *et al.*, 2000).

1.5.3 Swallowing difficulties and respiratory health

Due to their neurological impairments, a further and significant risk for children with CP during feeding, is the aspiration of food into the lungs due to an inadequately protected airway during swallowing (referred to as an incomplete swallow), coupled with a poor cough reflex. The usual causes of an incomplete swallow are a delayed or absent swallow reflex (Yokochi, 1996), decreased or poorly coordinated pharyngeal motility (Mirrett *et al.,* 1994) and/or difficulties caused by poor stability of sitting position, head posture, jaw control, mouth posture, lip control, tongue control and slow oral transit times (Selley *et al.,* 2001).

Significant levels of aspiration during feeding have been reported in several studies of severely eating-impaired children (Helfrich-Miller, 1986; Rogers *et al*., 1994), with liquids aspirated more frequently than solids, and the frequency of aspiration increasing with the severity of the eating impairment (Mirrett *et al.*, 1994). Aspiration is often symptomised by coughing, however, using videofluoroscopic assessment, Mirrett *et al.* (1994) revealed that 68.2% of 22 patients with severe spastic CP (aged 7 months-19 years) demonstrated significant silent aspiration (ie. where a cough response was absent).

Apart from causing distress from aspiration (Sullivan *et al*., 2000), aspiration is known to predispose children to the development of recurrent chest infections and chronic lung disease (Berquist *et al.*, 1981; Loughlin and Lefton-Greif, 1994; Dahl *et al.*, 1996; Sullivan *et al.*, 2000; Reddihough *et al.*, 2001). 31% of the children in the Oxford Feeding Study (Sullivan *et al.*, 2000), had suffered at least one chest infection in the previous six months, and a significant correlation was seen between the number of chest infections and the severity of the motor impairment.

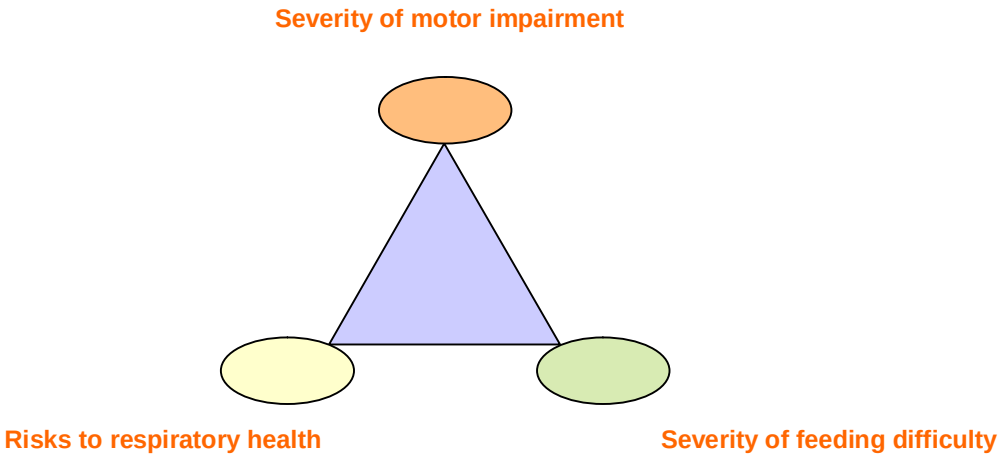


Figure 1.3 Relationship between motor impairment, feeding difficulties and risks to respiratory health.

The risks associated with aspiration are further complicated by the presence of gastro-oesophageal reflux, observed in 86% of children with cerebral palsy (Carr *et al.*, 1997) in which the gastric contents of the stomach return to the oesophagus. Aspiration of refluxed gastric contents, which are acidic in nature, results in more significant respiratory disease (Terry and Fuller, 1989 cited in Loughlin and Lefton-Greif, 1994; Schwartz *et al*., 1980). GOR has additional detrimental effects on oral health, through the erosion of primary and permanent teeth (Su *et al.*, 2003).

The consequences of aspiration pneumonia are serious, and it has been identified as the most common cause of death in children with feeding difficulties (Patrick *et al.* 1986; Reddihough *et al*. 2001).

1.6 Caregiver feeding practices, feeding difficulties and nutritional intake

It is suggested that the lack of ability to communicate, forage for food or self-feed in this population, puts these children at even greater risk of undernutrition (Reilly, 1990; Vik *et al*., 2001). They are reliant on the food offered to them by their caregivers and Reilly and Skuse (1992) observed that less food was actually offered during mealtimes to the disabled children in their study than to their non-disabled counterparts. With respect to malnourishment in non-disabled children, much attention is being given these days to the role of the caregiver and their feeding practices. In 1997, The United Nations Children's Fund (UNICEF) developed a conceptual framework which would provide community members, UNICEF programme staff and government counterparts the means of assessing existing care practices and environmental influences, in order to enable the interventions that would improve care practices at the household level that are associated with nutrition (Engle *et al*., 1997). In addition to this, the World Health Organisation (WHO) organised a consultation of 'experts' in complementary feeding in March 2003, from which detailed guidelines were produced in a special issue of Food & Nutrition (Dewey, 2003).

Poverty (Yousafzai *et al*., 2003), lack of available time (Das *et al.*, 1992; Yousafzai *et al*.; 2003 Pelto *et al*., 2003) and caregiver education (Guldan *et al*., 1993) are known to impact on children's nutrition. Increased education is particularly associated with more responsive feeding practices such as the increased frequency of feeding, freshness of food, commitment to more labour-intensive childcare and the provision of a protected and cleaner environment for feeding (Guldan *et al*., 1993).

Nonetheless, differences have been observed in the nutritional status of children amongst equally poor families. This can be attributed to the innate level of responsiveness in the feeding practices of the individual caregiver; children of more responsive carers have been observed to actually eat more (Engle, 1998, cited in Moore *et al*., 2005; Pryer *et al*., 2004). Non-responsive caregiver behaviours are associated with child rejection of food (Ha *et al*., 2002) and harsh or rigid caregiver interactions, where threats or 'physical intrusions' used to encourage eating can also lead to increased fussiness and food refusal (Black *et al.*, 1996 cited in Black, 1999). Thus, high or overbearing maternal promotion of feeding has been shown to result in greater weight faltering and failure to thrive (Wright *et al.* 2006).

The principal components of responsive feeding practices, as outlined by Engle (2000) include caregiver sensitivity to the child's psychomotor abilities for self-feeding, (thereby providing appropriate physical help and utensils to feed), responsiveness to the child's cues (including feeding at early signs of hunger), the active encouragement of feeding through positive verbalisations, coupled with a degree of patient persistence and feeding in a protected and comfortable environment. Feeding difficulties in disabled children appear however to influence caregiver-child interaction during mealtimes. Reilly and Skuse (1992) observed a marked lack of verbal interaction during feeding, which was not necessarily mirrored outside mealtimes. Satter (1990) suggests that in situations where parents are concerned about their child's feeding, there is a greater risk that parents will try to encourage eating through the use of overactive, forcing tactics. Black (1999) suggests that where caregivers' competence has been undermined by their children's feeding problems they may feed in a more rigid and controlling fashion as a consequence of increased anxiety. The level of caregiver responsiveness is also known to be associated with the degree of a child's disability. When observing caregivers of children with CP of varying degrees of severity, Sayre *et al*. (2001) noted a greater level of caregiver sensitivity with those children who had milder CP. In a study by Brooks-Gunn & Lewis (1984) with mothers of disabled children, levels of maternal responsiveness were seen to be related to their child's mental age, and mothers of the cerebral palsied children were overall less responsive than those of the children with Down's Syndrome or Developmental Delay. Satter (1990) states that optimal interaction between caregiver and child depends partly on the child's ability to communicate. In studies on non-disabled children, mothers used more active verbal encouragement during feeding when their children themselves were more active communicators (Moore *et al*., 2005). The communication skills of children with CP are restricted however, characteristically passive (Pennington and McConachie, 1999) and their cues more difficult to read (Reilly and Skuse, 1992). According to Black (1999), lack of caregiver sensitivity and misinterpretation of their child's behaviours can also lead to more rigid and controlling feeding methods. Caregiver mental health is an important influence on feeding style. Hurley *et al.* (2008) observed maternal stress to be significantly associated with a forceful and uninvolved feeding style, and maternal anxiety with a restrictive, forceful and uninvolved feeding style and conclude that mothers reporting stress, depression or anxiety symptoms are more likely to display non-responsive feeding styles. Anxiety and depression are cited by Coulthard and Harris (2003) as being significantly associated with food refusal.

Responsiveness is also bound to cultural norms (Pelto *et al*., 2003). In Bangladesh, Moore *et al.* (2005) found that the feeding style of caregivers with their non-disabled

children was particularly controlling and negatively coercive and Zeitlyn *et al.* (2002) describe the influence of local beliefs on the diet of young children and a widespread underestimation of child appetite. Likewise, environmental factors such as family function, and the effects of competing demands on the caregiver's time, play an important role in the ability to be responsive (Pelto *et al*., 2003).

Lack of responsiveness may, in part, account for the unexpectedly short length of mealtimes observed in the studies by Reilly *et al.* (1996) and Yousafzai (2003a), and has been attributed as the cause for premature cessation of mealtimes observed in feeding groups with non-disabled children (Moore *et al*., 2005). Possible reasons for this amongst caregivers of disabled children might include a misinterpretation of the child's communications (Reilly and Skuse, 1992; Black, 1999), or indeed, the difficult and stressful nature of feeding a child with disabilities (Sullivan *et al*., 2002; Reilly and Skuse, 1992). It may also be, in part, due to poor nutritional or feeding knowledge amongst carers (Verrall *et al*., 2000). Children's behavioural problems may also play a role (Palmer, 1978; Richardson 1988).

With the elevated risks of reduced caregiver sensitivity and responsiveness during mealtimes, added to the fact that disabled children have a high degree of physical dependence on their carer for feeding, caregiver feeding practices deserve particular attention. It should be noted however, that in a study by Welch *et al.* (2000), the children's oral-motor impairment was a greater predictor of feeding success than maternal sensitivity (ie. responsiveness to cues).

1.7 Emotional consequences associated with feeding and disability

Feeding difficulties have a significant impact on the emotional well-being of both the child and caregiver. Stress experienced on the part of the caregiver is often reported. According to Edelbok-Tysk (1989), feeding is one of the most time-consuming aspects of the care load of patients with CP. Sullivan *et al*. (2002) suggest that carers' recognition that their child with feeding difficulties is underweight may be a cause of stress. The experience of mealtimes is another source of strain, with half of the study mothers reporting to Reilly and Skuse (1992) that they were currently having great difficulty in feeding their children and 43% of parents in the Oxford Feeding Study reporting feeding their child with a disability as stressful and not enjoyable (Sullivan *et al*., 2000). In the latter, specific difficulties were identified as particular contributors to the stress experienced, and included the presence of a high degree of motor deficit, drooling, choking with solids or liquids, a high level of help required with feeding, and extra time or money required in food preparation. These last two factors were also identified as particularly problematic for carers in the developing world (Yousafzai *et al.*, 2003a). Raina *et al*. (2005) who studied 468 families in Canada discovered that the most important predictors of caregiver well-being (psychological as well as physical) were child behaviour, care giving demands and family function and recommend that interventions are family centred rather than being short-term technical rehabilitation interventions focusing primarily on the child.

It is recognised that the extra burden of care experienced by caregivers of disabled children can cause a high level of psychological disturbance (Reilly and Skuse, 1992; Mobarak *et al*., 2000) and has been known to be associated with depression (Hirst, 1985 cited in Reilly and Skuse 1992). In resource-poor countries, pressures caused by the burden of care are particularly great, where the majority of families are already living in difficult conditions, with little money and few services available. Furthermore, in countries such as Bangladesh, women comprise the poorest and most vulnerable group even within the 'hard-core' poor (Sen, 1997 cited in Mobarak *et al*., 2000) therefore putting these mothers at a double disadvantage (Ong, *et al*., 1998; Singhi *et al*., 1990). Cultural beliefs can add to the problem, whereby the family can suffer social stigma (Croot *et al*., 2008) and the parents are often blamed for the child's disability (Shah, 1995 cited in Bywaters *et al*., 2003). In a study by Mobarak *et al.* (2000), 41% of female caregivers with disabled children in Bangladesh scored above the cut-off for potential psychiatric morbidity. The main sources of stress identified by Mobarak *et al.* (2000) were child behaviour problems, age of the child (caregivers of older children

were significantly more stressed) and household income. Other socioeconomic factors were not associated with increased stress.

Apart from overall adaptation to the disabled child being affected by stress (Mobarak *et al.,* 2000), certain aspects of care and caregiver perception have been specifically associated with it. In terms of care, Boyle, (1991 cited in Reilly and Skuse, 1992) states that mental health issues can impair the carer's ability to provide effective overall nurturing and Harpham *et al*. (2005) found a relationship between maternal mental ill-health and poorer child nutritional status in non-disabled Asian children. With regards to perception, Reilly and Skuse (1992) noted a significant discrepancy between caregiver reports of length of mealtime and the researchers' observations, especially in relation to children with more severe feeding problems. They suggest that this may be related to mental health issues, which are known to affect the accuracy of caregiver reporting (Moore *et al*., 1988). It could also be suggested that the distorted perception of mealtime length may also be a reflection of the difficult nature of mealtimes, with brevity of mealtimes being associated with severity of difficulty.

"Feeding is not only a time for meeting children's nutritional needs but also an important opportunity for social interaction. Caregivers help their children build expectations around food and mealtimes. Children, in turn, learn to interpret and satisfy feelings of hunger and satiety through feeding. A partnership develops whereby children and caregivers communicate with one another, forming a basis for the emotional attachment that is essential to healthy social functioning." (Black,1999, p.217).

This partnership is partly dependent on the mental well-being of the caregiver. Depression can disrupt communication between the child and mother. According to Satter (1990, p.184), 'optimal interaction between parent and child depends on emotionally healthy, sensitive and responsive parents'. Murray (1992 cited in Southall and Schwartz, p.64) adds that a mother suffering from depression may either completely miss the child's signals or respond to communications at a physical level rather than emotional. Not only does this have implications for the level of responsiveness of the caregiver during mealtimes, but it has consequences for the caregiver-child relationship.

The importance of a strong parent-infant relationship has been observed in its protectiveness against the development of emotional, behavioural and health problems by researchers such as Carlson & Sroufe (1995), Fonagy *et al*. (1995), Greenberg

(1999) and Main (1996), as cited by Benoit *et al*. (2001). The 'feeding relationship' therefore plays a central role in the child's emotional development (Satter, 1990). Furthermore, caregiver inability to 'read' children's signals and insensitive responses to children's cues are presumed to lead to poor socio-emotional outcomes through poorly developed infant-carer attachment (Benoit *et al*., 2001). Satter (1990) points out that the longer any disruptions in feeding interactions persist, the harder they are to correct.

Finally, the quality of life of the whole family can be affected by the feeding difficulties of the disabled child. In a study by Vik *et al*. (2001) in which 26% children had oromotor dysfunction and 33% were unable feed themselves, 15% of parents reported that the family's quality of life was significantly impaired by the feeding problems of the disabled child.

1.8 Reported interventions

Where services exist, recognised interventions for children with cerebral palsy and feeding difficulties usually involve dietary treatments, the use of compensatory feeding strategies, remedial feeding therapy and medical treatment for GOR. Dietary treatments include the introduction of a high calorie diet and food supplements given orally or enterally. Compensatory strategies include positioning the child in a particular way ('postural alignment'), preparing food to a particular texture/consistency, the use of specific of feeding utensils and adjusting the amount given per mouthful and the speed of delivery. Remedial therapy refers to the introduction of sensorimotor exercises of the lips, tongue and cheeks, and exercises to practice chewing, aimed at improving oromotor skills for feeding. Where feeding through oral means is extremely effortful and it is not possible to minimise the risks of aspiration through the use of compensatory strategies, food and drink is given partially, or exclusively, through non-oral means (usually via a gastrostomy tube).

Some effectiveness and efficacy studies have been conducted to evaluate feeding interventions for disabled children, however most of these have been carried out in well-resourced countries. The interventions evaluated tend to be either time-intensive (as in the case of sensori-motor therapy), or require significant medical and financial input (as with enteral tube-feeding), none of which are viable to the majority of people in the developing world due to resource limitations both at the level of services and within the home. Studies evaluating interventions more appropriate to the environment of Bangladesh are hard to find.

The information available is further compromised by methodological limitations arising in many of the studies conducted to date. Reilly and Perry (2001) highlight the negative impact of the lack of standardised and validated formats for the clinical assessment of feeding, both at the oral and pharyngeal level. Studies are further limited by the nature of the study population, which, due to relatively low prevalence levels and a high degree of physical heterogeneity, leads to small sample sizes, non-randomised subject recruitment methods and problems in setting up control groups due to difficulties with matching. Control groups are also difficult to arrange due to the need for equipoise (offering an equal but alternative service) which is not always available.

Lack of clarity over terminology as well as specificity regarding the type and severity of disability in the sample group, also mean that the information gathered in many of the studies is difficult to interpret fully.

The outcomes from effectiveness studies, evaluating the impact of a combination of clinical approaches to the management of feeding difficulties in this population, are generally good. A study carried out in the United States by Schwarz *et al*. (2001) on 79 children with moderate to severe disabilities and feeding or nutritional problems, concluded that diagnosis-specific treatment of feeding disorders leading to a tailored intervention package can result in significantly improved energy consumption, nutritional status and morbidity (reflected by reduced acute hospitalisation rates). The interventions in this study involved both supplemented oral feeding as well as the use of alternative feeding, the former considered adequate only for those children who were not showing aspiration. In a series of case studies, Gisel and colleagues (2003) observed improvements in respiratory health and weight gain as a result of altered positioning, treatment for GOR and the modification of food texture to minimise aspiration from swallowing. In India, Gangil *et al.* (2001) evaluated the interventions they provided to 100 children with CP and feeding difficulties. The children and their caregivers were seen weekly or fortnightly for a minimum of 3 months. Intervention was tailored to meet the child's needs and included training caregivers in the use of compensatory strategies and remedial therapy. Nasogastric tube-feeding was also performed during acute illness. Results from the evaluation showed improvements in all aspects of the children's ability to manage food. They also recorded fewer chest infections post intervention and improvements in the nutritional status in 40% of the cases. Although access to details of the study are limited, this study is worthy of note as it is one of the rarely published studies of its kind conducted in a developing country. The authors raise issues of particular relevance to disabled children and their families living in the developing world such as the impact of general caregiver knowledge on disease, disability and associated problems and also suggest that the psychological impact of having a child with severe chronic disability prevents caregivers from appreciating the full significance of their children's feeding difficulties.

Researchers have also attempted to evaluate specific aspects of the clinical interventions typically provided. Decreased aspiration levels have been achieved through postural alignment alone (Larnert and Ekberg, 1995) and the positive impact of modifying food textures on aspiration levels (Helfich-Miller *et al.*, 1986; Rogers *et al.,* 1994; Gisel *at al*., 1993) as well as oromotor skills (Helfrich-Miller *et al*., 1986, Gisel *at al.*, 1995) has also been investigated.

The efficacy of sensorimotor therapy in terms of improving nutritional intake has been studied, and improvement in skills such as chewing, tongue lateralisation, lip closure,

and spoon feeding (Gisel *et al.,* 1996), as well as reducing spillage and residue of food in the mouth after swallowing (Gisel *et al.*, 1995) have been observed in children with moderate impairments. Changes in overall length of mealtime and weight gain were not significant, however the children's feeding skills achieved a greater degree of maturation and 'normalisation' in terms of textures they could manage and feeding patterns observed. Nonetheless, Gisel *et al.* (1995) suggest that only children with mild-moderate impairments can benefit from sensorimotor therapy, and that, even then, neither texture modification nor sensorimotor therapy alone, are sufficient interventions for most children to achieve adequate calorie intake.

Research into the impact of nutrition therapy has focussed on the effects of high calorie feeds given nasally or enterally, although benefits from high calorie foods given orally have also been observed (Evers *et al.*,1991; Reilly and Skuse,1992). Research into the success of tube-feeding has shown that significant catch-up growth is possible in this population (Patrick *et al.,* 1986; Corwin *et al.,* 1996). However, Rempel *et al*. (1989) conclude that gastrostomy feeding does not eliminate growth retardation and highlight certain medical contraindications. Furthermore, Patrick et *al*. (1986) discuss the difficulties reported in the re-establishment of previous levels of oral feeding, where tube-feeding is used as a temporary intervention and Sleigh, Sullivan & Thomas (2004) review the conflicting evidence arising from the research with regard to the potentially exacerbating effects of gastrostomy on respiratory illness, GOR, and mortality. They also caution that patient satisfaction reports vary and the cost implications are considerable.

There have been no published studies on nutritional interventions with the disabled population in Bangladesh, however, literature exists on the effectiveness of nutrition interventions with non-disabled children. The studies are included to illustrate the potential benefits of such interventions, in Bangladesh, in cases where feeding difficulties do not exist.

Several studies have compared the effectiveness of education versus supplementation. The following two studies suggest that education alone is effective but education plus supplementation is more effective still.

The first of these studies was conducted by Roy *et al*. (2005) with 282 children aged 6-24 months in rural Bangladesh. Carers received 3 months of education in nutrition and care practices, twice weekly, with or without supplementation (whilst the control group received usual services from the National Nutrition Programme), followed by a three

month observation period. Children whose carers received education only, showed a mean increase in weight of 0.91kg in the first 3 months, followed by an additional 1.26 kg during the observation period. Children receiving education plus supplements increased in weight by 1.06 kg, followed by a further 1.16kg. The differences in weight gain between the groups were not statistically different although increases in height were. After six months, 59% of the group who had received education only and 86% of those who had received education plus supplementation had improved from moderately impaired to mild or normal nutritional status. The second group made better gains in spite of suffering a higher incidence of morbidity suggesting that supplementation in addition to education does lead to better outcomes in the long term.

The second study was conducted by Fauveau *et al.* (1992) in a poor slum community of urban Bangladesh. Again, they evaluated nutritional education versus education plus a supplementary feeding programme. The intervention was for six months. Significantly greater weight gain was observed in the education plus supplement group in the first three months although there was no difference between the groups at the second review. The authors suggest however that this may be due to seasonal and epidemiological factors.

In terms of successful carry-over, a study by Khanum *et al.* (1998) followed up 437 slum children aged 1-5years who had been treated for acute malnutrition at the Children's Nutrition Unit in Dhaka. Twelve months after being discharged at 80% WH, their mean WH was 91%. However, the mean WAZ was -4.14, which the authors account for by the extremely high incidence of ill-health (diarrhoea and pneumonia) in this group.

What is revealed in the literature concerning Bangladesh however, is the cost implications of improving children's diet. Brown *et al.* (1993) suggest that to fill the energy gap of the average weaning-age breastfed Bangladeshi child it would cost approximately 8% of the parent's daily wage. In their study, the increase in food intake equivalent to 2% of a daily wage, achieved through nutrition education, did result in significant improvements in child weight gain however they were not clinically satisfactory. Cost implications were reported by carers of disabled children in the Indian study by Yousafzai *et al*. (2003c), as the main barrier to improving the nutrition of their disabled child.

The following tables summarise key intervention studies cited in this thesis.

Table 1-5 Studies from high-income countries

Authors & location	Aim	Participants	Methods	Outcome
Nutrition therapy				
Evers *et al*. (1991)	Evaluate the impact of a programme of nutritional rehabilitation through increased calorific content and quantity of food given. Fluid intake also monitored.	*N*=15 Aged 7-27 years. Severe physical and developmental disabilities. Residential care.	Calculated recommended daily intake for each person. Increased caloric density of meals by increasing the fat content of the diet. Increased quantity offered and offered snacks.	Overall significant improvements in all anthropometric measures after 6 months. Some individuals improved more than others. Mean weight gain: 2.7kg (*SD* 0.5, p<0.001) Fluid intake increased from a mean of 556ml to 716ml per day.
Patrick *et al*. (1986) CANADA	Evaluate correction of wasting – comparing naso-gastric (NG) tube-feeding with best oral feeding.	*N*=10 Aged 2-15years Severe neurological deficits. Attending a regional child neurological centre.	Randomised Control Trial of intensive feeding via NG versus standard feeding for children with severe CP & wasting (based on skinfold measures below 5th percentile for age & failure to gain weight in previous year). Patients acted as own controls + comparison between patients. Stopped after plateau in weight gain (4-5 wks later)	Significant weight gain in all tube fed individuals (p<0.01). 10-46% bodyweight increases achieved, with 50% increase in energy intake. Benefits: healing of pressure sores and correction of cold & cyanosed extremities. Reported decreases in spasticity and improved affect.
Corwin *et al.* (1996) USA	To document catch-up growth in first 18m after gastrostomy tube (GT) surgery.	*N*=75. Diagnosis: failure to thrive. 49% CP. 0-6.5years. (GT placed any time from birth).	Repeated measures of weight & length: At surgery, after 12 m, after 18m.	Significant catch–up growth (height, weight, & WH by 12m after surgery) in all non-ambulatory children. Best results in children with CP. At 18m post surgery, WH catch-up expressed in p-values for CP population = 0.01

Authors & location	Aim	Participants	Methods	Outcome
Sensori-motor therapy				
Gisel *et al.* (1995) CANADA	Effect of oral sensorimotor therapy on growth, eating efficiency & aspiration in children with CP & feeding problems	*N*=27 Mod-severe CP. Mean age of the 3 groups: 4.8, 5, 5.4 years. Special schools. Selected if could eat solid or puree within 1 & 2SD of estimated time norms	3 groups. 1: 20 weeks therapy, 2+3: 10 weeks normal routine, 10 weeks therapy (Group 3 = aspirators). Therapy: 5-7 minutes daily, 5 days a week. Tailored. Based on Kenny's subtest: Functional Feeding Assessment. Mainly: tongue lateralisation, lip control and vigour of chewing. Weight, skinfold measures & videophotography	Mean treatment compliance was 62-70%. 26% aspiration (fluids only). Only 1 in 7 coughed when aspirated. Groups 1& 2: No change in time to chew, but there was for group 3, also significant increase in number of those children who could managed a more chewy texture after treatment. Significant improvement in lip control, biting, chewing & swallowing. But no significant change in time for meals / snacks, though marginally significant number were eating more textured foods at 20 weeks. Therefore maybe less spillage, less residue after swallows and therefore increased intake. No significant changes in weight or skinfold. Conclusion: ▪ Eating efficiency may not be a useful outcome measure. ▪ Sensorimotor therapy beneficial for children with only mild-mod impairments and not sufficient alone for adequate calorie intake for most. ▪ Propose a classification system based on growth (weight, height & skinfold) & eating skills (eating efficiency & oral motor skills) in order to determine most appropriate therapy for each child.

Authors & location	Aim	Participants	Methods	Outcome
Postural alignment				
Larnert & Ekberg (1995) SWEDEN	Evaluate impact of neck and body positioning on oral & pharyngeal function in children with severe CP & feeding difficulties.	*N*=5. Severe CP - tetraplegia and dystonia. 3-10 years. All had gross aspiration & posterior leak. Targeted selection.	Examined using videofluoroscopy.	With neck flexion & body in 30 degrees reclined sitting position - aspiration decreased in all 5 -oral leak decreased in 2

Nutrition therapy & feeding strategies (high and low tech)				
Schwartz *et al.* (2001) USA	Effects of nutritional intervention on energy consumption, weight gain, growth and clinical status.	*N*=79. Moderate-severe developmental disabilities and feeding / nutritional problems Mean age 5.8 +/- 3.7 years	2 year programme: Mixture of medical treatment for GOR, remedial therapy and compensatory strategies for feeding (low & high tech – ie. from supplements to gastrostomy) Tailored interventions based on diagnosis	Significant improvements in energy consumption & nutritional status observed in all groups. Increases in weight ($p<0.01$) & height ($p<0.05$). Significant decreases in hospitalisation related to feeding problems ($p<0.01$). Oral nutritional supplements are sufficient to achieve nutritional adequacy in patients NOT showing aspiration.

Authors & location	Aim	Participants	Methods	Outcome
Feeding strategies & nutrition therapy (predominantly low tech)				
Gisel *et al*. (2003) CANADA	Examine whether pulmonary function would improve following 1 year of intervention aimed at minimising aspiration from swallowing.	*N*=3 case studies. Aged 18-43 months CP with severe motor impairment All <5th centile (ie. <-1.6 z-scores) in WA.	Tailored programme comprising altered positioning, treatment for GOR, modification of food texture (to reduce risk of aspiration and effort in feeding) and high calorie diet. Oral-motor exercises taught to mother (promote lip closure, minimise bite reflex, maximise food transit time).	Results from 2 of the 3 cases: 28% & 45% improvements in lung function. All 3 maintained weight and 1 showed small catch-up.

Table 1-6 Study from low-income countries

Feeding & nutrition therapy (predominantly low tech)				
Gangil et al. 2001 INDIA	To determine the magnitude + extent of feeding problems in children with CP and the effectiveness of nutritional interventions.	*N*=100.CP. Aged 1-9 years, mean 2.5	Remedial therapy & compensatory strategies including NG tube feeding during acute illness. Education to families on CP. Seen weekly or fortnightly for a min of 3 months.	Improvement seen in all aspects of children's ability to manage food. Fewer chest infections. Improvements in nutritional status in 40% of cases.

1.9 Summary of study background

Children with CP and feeding difficulties are a vulnerable group. They are at high risk of malnutrition, respiratory disease and the negative consequences on health and general functioning associated with these. They are also at risk of neglect and abuse from caregivers, as a result of the stresses related to caring for a child with chronic high support needs.

Whilst some research exists on the effectiveness of certain interventions for this population, it has been conducted mainly in well-resourced countries where the medical options for intervention are greater and even low-tech strategies have some cost implications. Nonetheless, adequate research into the effectiveness of these interventions is still lacking (Reilly and Perry, 2001; Gisel, 2008). Research available on appropriate interventions for children and their families in resource-poor environments, where the negative impacts of feeding difficulties may have more serious consequences, is almost non-existent.

1.10 Study environment and location

1.10.1 Study environment

The study was conducted in Dhaka, the capital city of Bangladesh, which is situated in Southern Asia, bordering the Bay of Bengal, between India and Myanmar.

Figure 1.4 Map of Bangladesh

Bangladesh has a total area of 147,570 square kilometres and a population of approximately 142 million, being one of the most densely populated countries in the

world. Dhaka city alone has a population of approximately 10 million (Bangladesh Bureau of Statistics, 2009). The gross national income (GNI) per capita in 2006-7 was US$520 and the literacy rate of adults in Dhaka in 2008, was 57.3% (Bangladesh Bureau of Statistics and UNESCO, 2008). Data collected in the last five years report 29.9% of children under the age of five years, living in urban areas, to be moderately or severely underweight (mean $WAZ_{(WHO)}$[5] -1.40, *SD*1.21; mean $MUACZ_{(WHO)}$ -1.34, *SD* 0.80) with figures increasing in the rainy season (Bangladesh Bureau of Statistics, 2005). There is one registered physician to a population of 3866 (Bangladesh Ministry of Education, 2003) and only 51% of urban births are attended by trained personnel (Bangladesh Bureau of Statistics, 2005). In 2006, the national under-five mortality rate was 69 per 1000 live births (UNICEF, 2008).

Key statistics are summarized in table 1-7 below.

Table 1-7 Summary of country statistics

Population (2008)	142,000
GNI per capita (2006-7)	US$520
Literacy (2008)	57.3%
Under-5 mortality rate (2006)	69/1000
Percentage urban children <5 years moderately or severely underweight (2005)	2.29%

Studies conducted in Bangladesh have identified that poverty, seasonal variation in food production, variability in food distribution to and within families, and a general lack of education all impact on the type, amount, frequency and freshness of food eaten as well as food hygiene and the cleanliness of feeding location (Begum *et al.*, 1979; Brown *et al.*, 1982; Das *et al.*, 1992; Guldan *et al*., 1993; Zeitlin and Islam, 2002). The quantity of food eaten by children in Bangladesh is believed to be further compromised by caregiver feeding practices, which are traditionally very controlling and unresponsive to children's communications (Moore *et al*., 2005). General ill health and frequent sickness, a particular risk to children with cerebral palsy (Fung *et al*., 2002) would further impact on food intake and nutritional status.

National figures for the prevalence of cerebral palsy in Bangladesh are not available. However, an overall prevalence rate of 4 per 1000 for serious motor impairment was indicated by an epidemiological study on children aged 2-9 years (*N*=4005) conducted in a Northern district of Bangladesh in 2001-2002 (Ferdous *et al*., 2005), a high percentage of whom would have had CP. Although the risk factors for CP in Bangladesh are high, the mortality rate amongst this population is also high, identified at 8.7% in a group of 92 children with CP (mean age <5 years) who were followed for

[5] Using the WHO growth reference standards 2005

up to three years (Khan *et al.,* 1998). (In our study, one child died shortly after the study and two others were hospitalised during the programme).

The majority of the children with CP receiving services in Bangladesh are from poor families (Khan *et al.*, 2006). The mothers usually have little or no education, with national literacy rates for women in the year 2000 at 29% (Bellamy, 2004). Beliefs around the cause of childhood disability usually involve maternal blame, which contributes to the mothers' feelings of helplessness. Stress levels amongst mothers of children with CP in Bangladesh have been identified as high. Mobarak *et al*. (2000) demonstrated that 41.8% of the 91 mothers of children with CP they interviewed were at risk of psychiatric morbidity, with a direct association observed between level of care burden and the presence of stress.

In Bangladesh, hospitals do not routinely provide services for children presenting with disabilities (Khan, 2005). Services for neurologically disabled children in Bangladesh comprise a network of approximately 10 specialist units or centres, some of which are housed in teaching hospitals and the majority of which are in the Dhaka area. Most of these units are staffed by specialist Paediatricians and Developmental Therapists who have received basic training. Qualified Physiotherapists and Occupational Therapists are occasionally employed. The majority of children with disabilities live in the rural areas, some of whom can access help from primary healthcare fieldworkers, who have received basic training in the management of CP from non-government organisations (NGOs) operating in certain districts. However, even in Dhaka, where the majority of the services exist, many children are still not being reached.

1.10.2 Study location

The study was located at the Child Development & Neurology Unit of the Dhaka Shishu Hospital, and in homes in three surrounding slum areas (Mirpur, Mohammadpur and Rayer Bazar). The hospital is Bangladesh's national children's hospital, and the centre offers an outpatient and inpatient service to children with developmental delay, disability and childhood illnesses. It runs a busy outpatient service for new referrals and children on review, a more in-depth assessment and intervention service for children with complex needs, and runs a ward for cases requiring hospitalisation. The unit is staffed by doctors and Developmental Therapists who work together to provide a holistic intervention. The latter have informal training and perform to the level of a Generic Therapy Assistant in the UK. The unit also provides training to satellite child development centres in Dhaka and in one district outside the city, and chairs a national

disability network, the Shishu Bikash Network. The unit is mostly independently funded but is housed within a government hospital.

Mirpur, Dhaka

Dhaka Shishu Hospital

Rayer Bazar, Dhaka

Figure 1.5 Examples of study locations

Chapter 2

Methods

2 Methods

This chapter outlines the study aims, objectives and contextual framework. It describes the study design, recruitment, details the outcome measures, data collection methods and tools (including the reliability thereof), intervention methods and methods of data analysis.

2.1 Study aims and objectives

The aims of this study were to design, implement and evaluate the impact of an intervention programme appropriate for children with CP and feeding difficulties living in a resource-poor environment, and use the results to inform appropriate service development for this population and their caregivers. The aims were based on the following key findings from previous studies, outlined in detail in Chapter 1:

- Children with cerebral palsy (CP) and feeding difficulties generally suffer from moderate-severe secondary malnutrition (Thommessen *et al.*, 1991a, 1991b, 1991c; Stallings *et al*., 1993a, 1993b; 1996, Dhal *et al.*, 1996; Troughton and Hill*,* 2001; Fung *et al*., 2002), which impacts on their overall health and functioning (Samson-Fang *et al.*, 2002; Tomkins and Watson, 1989; Khan *et al*., 1998; Sullivan *et al.*, 2000). They also suffer a high risk of aspiration pneumonia which is the commonest cause of death in this population (Patrick *et al.*, 1986; Reddihough *et al.*, 2001).
- Feeding difficulties cause very high levels of stress to the caregivers of these children. (Reilly and Skuse, 1992; Sullivan *et al*., 2000).
- The feeding practices of these caregivers are reduced in responsiveness[4] (Satter, 1990; Reilly and Skuse, 1992; Black, 1999; Sayre *et al*., 2001; Hurley *et al.,* 2008).
- Mealtimes are often distressing for the child (Sullivan *et al.,* 2000).
- Services for these children and their families are generally inadequate (Sullivan *et al*., 2000), and in resource-poor countries, very scarce. (Mobarak *et al*., 2000).
- Very little research has been carried out into the effectiveness of low-technology approaches to the long-term management of feeding difficulties in this population (Reilly and Perry, 2001).

[4] ie. frequency and amount of food given, appropriate physical support for self-feeding and sensitivity of feeding manner

2.2 Ethical approval

Ethical approval was obtained from the Ethical Review Committees of The Institute of Child Health, University College London, and The Bangladesh Institute of Child Health, Dhaka.

2.3 Intervention overview

The intervention aimed to promote child health and well-being through maximising children's nutritional intake, minimising the risks of chest infection associated with feeding, and reducing the levels of discomfort and distress experienced by the children during feeding. This would be achieved through increasing the responsiveness and sensitivity of caregiver feeding practices, promoting positive interactions during feeding and minimising negative or abusive ones, thereby also improving the well-being of the caregiver in relation to stresses incurred due to the feeding difficulties of their children. The overall effectiveness of the intervention would be evaluated with respect to these aims, and factors affecting caregiver compliance reported.

A programme was designed that would be accessible to children and mothers from low socio-economic levels and an environment with limited health resources. Non-invasive medical procedures and minimal cost implications, both in terms of money and time, were central to the design.

Various interventions for this population, involving both high and low technology methods, are described in the literature, some of which and have been outlined in Chapter 1. Recommendations by researchers include:

- An emphasis on early identification and intervention (Gisel and Patrick 1988; Motion *et al*., 2002).
- Working with caregivers to reduce the impact of feeding difficulties (Thommessen *et al*., 1991; Gangil *et al*., 2001), in particular with female caregivers (Socrates *et al*., 2000).
- Tailored interventions based on individual assessment (Gangil *et al*., 2001; Schwartz *et al*., 2001, p172; Sullivan *et al*., 2002)
- A multidisciplinary approach (Reilly *et al*., 1996) especially in an environment of widespread malnutrition and infection (McConachie *et al*., 2001).
- Home visiting as well as clinic-based service (Reilly *et al*., 1996; Ashworth and Khanum, 1997; McConachie *et al.,* 2000, 2001).
- Consideration of the transport issues for the child and caregivers in the case of clinic-based interventions (McConachie *et al*., 2001).

- Addressing the needs of the caregiver as well as the child (Satter, 1986; McConachie 1994; Mobarak *et al*., 2000).
- Working with the family as a whole. Goals should be family-led (McConachie *et al*., 2000) and should and tackle the wider issues of food security, primary healthcare as well as caring practices (Pelletier, 2002).
- Viewing the child and family within the wider social system, thereby extending services to community empowerment rather than keeping within the medical model of health promotion (Laverack and Labonte, 2000).
- Peer education (Marsh *et al*., 2004).
- The use of locally available, sustainable and effective approaches (Marsh *et al.,* 2004).
- Developing new services that enhance existing services (Penny *et al*., 2005).

Based on these recommendations, an intervention programme was designed which focused on caregiver training tailored to each child and caregiver, incorporated home visits, involved caregiver groups and peer education, and was situated within an existing service to children with disabilities. Although the intervention would target the child's environment as a means to target the child's needs, wider issues such as food security and community empowerment were not addressed directly.

The model of intervention can be illustrated using the biosocial model of disability (see figure 2.1), which forms the basis of the WHO's framework for health and disability (the International Classification of Functioning, Disability and Health, 2001). The intervention would act at the level of *environmental factors* in order to impact on the individual's *activity* (improved feeding), and consequently on their *body functions*, *health* and *participation*, an approach which is consistent with the social model of disability. The caregivers were considered to be the key agents of change in this study whereby changes in the children's nutritional levels and their ability to eat and drink more safely, more efficiently and more happily would depend on changes in carers' feeding practices.

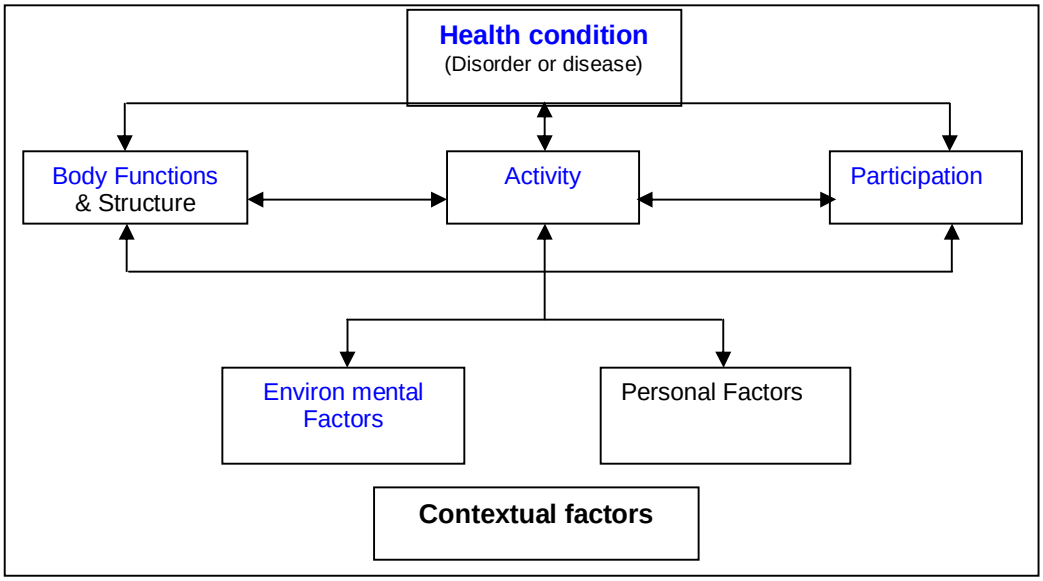


Figure 2.1 The biosocial model of disability, WHO (2002)

The content of the programme included caregiver training on how to improve their children's nutritional intake and levels of hydration and reduce the risks of aspiration and discomfort/distress experienced by the child during feeding. The strategies taught involved enhancing their children's diet, feeding in a responsive manner and employing specific feeding methods. Further details of this are given below (section 2.7).

Community level involvement was provided by the researchers during the baseline data collection, whilst the group training sessions were facilitated by staff working as Developmental Therapists in the child development centre of a tertiary hospital (see section 2.7 below).

2.4 Study design

The study was a prospective intervention study. Recruitment was achieved through opportunistic sampling methods.

Study design of a small, heterogeneous population is difficult (McConachie, 2002; Stanley *et al.*, 2000). Randomised control trials and comparative studies are limited by the lack of homogeneity in the CP client group and difficulty achieving sufficient numbers to counter this. Comparative studies are further restricted by the ethical requirement to provide an alternative but equal service, though such services are usually lacking. Efficacy studies are difficult to conduct because there are few discrete interventions. McConachie (1999) suggests research should initially be aimed at designing appropriate local services (ie. effectiveness rather than efficacy), and that once there is an adequate service base available, then comparative testing for efficacy of particular approaches may be possible.

McConachie (2002) advocates the use of scientific methods that enhance interpretation of outcomes, such as the use of an independent evaluator and the triangulation of different data, and suggests that naturally arising opportunities for some control, such as waiting times before intervention, can be taken advantage of. Stanley *et al.* (2000) recommend that outcomes should be measured according to all aspects of disability and therefore should include outcomes relating to physically measurable parameters, functional abilities (ie. a subject or carer's ability to complete a functional task effectively) and patient and carer satisfaction. They add to these, the measurement of cost-effectiveness. They advocate that intervention goals should be functional, specific and measurable using valid and unambiguous methods.

In line with these recommendations, the study design was largely non-comparative, evaluating an aspect of service provision, and involving a measure of control arising from non-intervention during a treatment waiting period, for one of the two cohorts. Data were collected in relation to physical parameters, functional ability and carer satisfaction and the intervention had a functional rather than impairment focus. A multi-method approach to data collection enabled a greater degree of accuracy of information (through cross-checking and clarification) and of validation of the results (Mays and Pope, 2000).

The study design involved a target of 35-40 child-caregiver pairs who would be trained in groups containing 4-5 pairs[5], resulting in a total of 8 groups being trained. The number of potential participants was limited by several factors. These included being able to identify sufficient numbers of appropriate children, caregiver willingness to participate, the hospital unit's capacity for running training groups and the researchers' capacity for conducting 2-4 home visits on each child-caregiver pair. Within these constraints, a total of 37 child-caregiver pairs were recruited into two cohorts (C1 and C2) which started the training groups at different times. This provided the opportunity for a control period whilst the second cohort awaited training. Random allocation to groups was not possible as insufficient numbers of children were identified during the initial recruitment attempt.

[5] This number was considered 'manageable' and advised by the head of department.

2.5 Recruitment

2.5.1 Inclusion / exclusion criteria

Children whose feeding difficulties were most likely to put them at risk of malnutrition and respiratory disease were prioritised. As a general guidance for selection, factors influencing practitioners' decisions for non-oral feeding in the West were used (Reilly *et al.,* 2000, p186), and the focus was on the more severely disabled, younger children (Dahl *et al.*, 1996). Children who were not being exclusively breast-fed were target as the needs of this group are quite different from those of children who are weaned. An upper age limit was also imposed, in a further attempt to achieve some degree of homogeneity within the study sample, whilst allowing for adequate numbers to be identified within our geographical limitations. The inclusion/exclusion criteria can be summarised as follows.

- Moderate-severe CP and reported or observed feeding difficulties
- Fully or semi-weaned
- Minimum of 1 year and maximum 11 years of age
- Absence of progressive, metabolic condition or chronic sickness (cardiac, renal, gastrointestinal), congenital syndromes
- Child not taking steroids or thyroxin
- Not receiving feeding services elsewhere

2.5.2 Recruitment methods

The participants were identified primarily through an NGO network of urban primary healthcare programmes based in the slum areas of Dhaka. Workshops were run for the NGO fieldworkers to inform them about the study and the types of children the researchers were hoping to identify. A total of four screening days were arranged in three sub-centres, targeted for their proximity to the hospital. The screening methods needed to be fast and accurate. For this reason, children with moderate-severe feeding difficulties were identified using a combination of basic information obtained from caregivers regarding the feeding difficulty and the child's rating on the GMFCS (Palisano *et al*., 1997), knowing that children with a greater degree of physical disability usually have a greater degree of feeding difficulty. Sixty child-caregiver pairs were seen, out of which thirty-four complied with the inclusion criteria. Of these thirty-four, three pairs subsequently declined participation. In order to increase the sample size, a further six pairs were recruited through the Shishu Hospital, having received some rehabilitation but no training regarding feeding.

Enrolment into the two cohorts (C1 and C2) is illustrated in figure 2.2 below, with C2 being enrolled towards the end of the C1 training period.

2.6 Data collection

2.6.1 Data collection time-points

C1 **April 2005** **-Feb 2006** 10 months	**Baseline (BSL)** Initial assessment & advice		**Training groups** 2 1/2 months	**Review 1 (PTR1)** 1st post-training review	**No input** 4-5 months	**Review 2 (PTR2)** 2nd post-training review
	n=16					

C2 **July 2005** **-Sep 2006** 14 months	**Baseline (BSL)** Initial assessment & advice	**No input** 3-4 months	**Post-advice Review (PAR)** Post advice review & advice reiterated	**Training Groups** 2 1/2 months	**Review 1 (PTR1)** 1st post-training review	**No input** 4-6 months	**Review 2 (PTR2)** 2nd post-training review
	n=21						

Figure 2.2 Study Design

Data for both cohorts were collected before intervention (Baseline), immediately after group training (PTR1) and again after a follow-up period of 4-6 months (PTR2). The usual time period for assessment and review was one to two months. The process varied in length for various reasons including the need for repeated home visits (due to finding the child or caregiver sick or absent on arrival at the house; telecommunications often not available for warning about such things), researcher sickness, or flooding and political unrest preventing travel.

Every child-caregiver pair was assessed at home, at least once, but in a few instances reviews took place in clinic settings, for reasons of security and access. There was an additional data collection point for C2, following their initial non-intervention phase and immediately prior to entering the groups (PAR). Basic advice (predominantly focusing on the limitation of risk of aspiration) was given at each assessment point and the equipment was given to all the children at BSL for ethical reasons. (There was a

chance that any child-caregiver pair might drop out before starting group training and therefore receive no further input). Comparison within the study was therefore between *advice plus training* and *advice only.*

Data were collected at each assessment point by the Principal Investigator (PI) and Research Assistant (RA). To counteract any risk of bias due to lack of blinding, scoring on the main study measure (Mealtime Observation Schedule; FORM 7) was checked by the PI after each assessment and later by an independent evaluator, using photographs and videos of the mealtimes observed.

Information was taken on a wide range of variables. This was important clinically, in order to make a thorough assessment of the initial needs of each child. Not all of the data was required for the evaluation of the study however, but is available for later discussion.

2.6.2 Outcome measures

2.6.2.1 Assessment areas, methods and tools

Following the principles of the ecological model of child development (Bronfenbrenner, 1979), and as recommended in feeding interventions (Black, 1999), this study approached the child and caregiver as an interactive unit, assuming that changes in one would affect the other. Data on the children, caregivers and mealtimes were therefore collected.

These data were required not only to guide the clinical process of determining and monitoring individual caregiver training needs but they were also used to measure any impact of the intervention on the child, caregiver and caregiver feeding practices, as well as allowing comparison with subjects described in previous studies. Information was also needed with regards to factors that can influence feeding (see figure 2.3 below) as well as factors that could potentially influence the study outcomes such as the relationship between financial status and maternal stress (Mobarak *et al*., 2000), financial status and nutritional intake (Yousafzai, 2003c), caregiver education and feeding practices (Guldan *et al*., 1993), and family support and patient compliance (Becker and Rosenstock, 1984, pp.175-208). Data were therefore obtained about the child's overall health status (including the existence of conditions such as epilepsy and gastro-oesophageal reflux), level of sensory, physical and intellectual functioning, general behaviour as well as their nutritional status and fluid intake, the degree of difficulty they had with feeding and their affect during mealtimes. Information regarding the socio-economic circumstances of the family, caregiver psychological well-being and

stress in relation to feeding, as well as caregiver feeding practices were also assessed. The majority of the data collected was quantitative (through objective measures, rated researcher observations and rated caregiver reports). The quantitative data was supported with open-ended questioning relating to caregiver's feelings with regards to the feeding problems and the feeding experience, their hopes and expectations from the training, their perceptions about changes in themselves, their child and family attitude following training, and caregiver satisfaction.

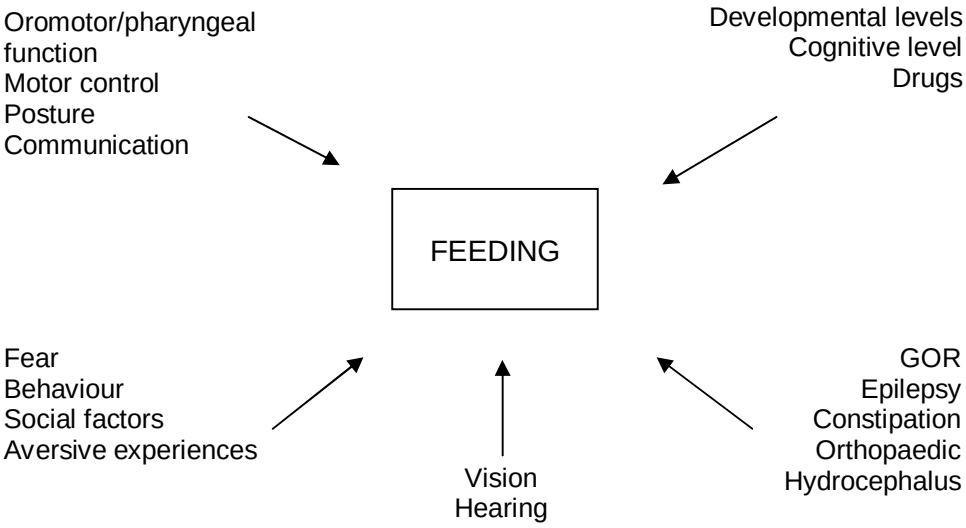


Figure 2.3 Factors that may affect feeding the child with neurological impairments (Reilly *et al*., 2000, p.154).

Details on the theoretical basis for the specific methods and tools used or adapted, are outlined later in this chapter. Table 2-1 below summarises the assessment areas and methods of data collection used. Feedback was also sought at the end of the programme with regards to caregiver satisfaction.

Recording methods included the use of record forms, video, photographs, RA observation sheets and a PI log book. A summary of the tools and measures used, and the areas each addressed, is given in tables 2-2 and 2-3 below. The forms can be found in the appendices**.**

Table 2-1 Assessment areas and methods of data collection

	Assessment area	Methods	Assessed by
CHILD			
1	Health & physical / sensory functioning	Caregiver interview, clinical observations (chest status, sensory skills, physical structure) and Gross Motor Function Classification System rating (GMCS, (Palisano *et al*., 1997),	Medical officer & Principal Investigator (PI)
2	Nutritional intake	Caregiver interview: 24 hour dietary recall, & one-month food frequency.	PI and Research Assistant (RA)
		Anthropometric measurements: Weight, mid-upper-arm circumference (MUAC), and demi-armspan.[6]	RA
3	Fluid intake	Caregiver interview: 24 hour dietary recall	PI & RA
4	Ability to manage food and drink orally and pharyngeally	Caregiver interview & naturalistic mealtime observation – coding presence of features indicating oral and pharyngeal dysfunction and rating frequency of occurrence of pharyngeal signs, using checklist.	PI & RA
5	Affect during feeding	Caregiver interview & mealtime observation. (Coded using a checklist of behaviours plus global frequency ratings).	PI & RA
CAREGIVER			
6	Socio-demographic information & hygiene awareness	Caregiver interview.	RA
7	Caregiver emotional status, level of support and motivational levels	Caregiver interview and SRQ20 (Harding *et al.*, 1980)	PI & RA
8	Time spent in feeding	Caregiver interview.	PI & RA
CAREGIVER FEEDING PRACTICES			
9	Food consistency	Caregiver interview & mealtime observation.	PI & RA
10	Child's position during feeding: trunk and head	Caregiver interview & mealtime observation.	PI & RA
11	Feeding methods – level of physical support, utensils used, speed, amount per mouthful, angle of delivery, manner of delivery	Caregiver interview & mealtime observation.	PI & RA
12	Caregiver's responsiveness and interaction style	Caregiver interview & mealtime observation.	PI & RA
13	Reasons for non-compliance, where observed	Caregiver interview.	PI & RA

[6] Measures for weight and height were taken to identify underweight and stunting. Weight, MUAC and Body Mass Index (BMI) were used to measure change in nutritional status as linear growth alone is a less representative measure of nutritional status in this population (Samson-Fang and Stevenson, 2000).

Table 2-2 Summary of tools and measures

TOOLS and MEASURES	ASSESSMENT POINT	AREAS ASSESSED
Socio-demographic interview (FORM 1; Appendix 4)	BSL	Household characteristics; employment; education; food procurement, hygiene awareness.
Poverty Mapping Questionnaire (FORM 2; Appendix 5)	BSL	Assets and selling of menial labour; education; health; social isolation; shelter food security; clothing.
SRQ20 (Harding *et al.*, 1980) (FORM 3; Appendix 6)	BSL, PAR, PRT1, PRT2	Depression (anxiety and somatic complaints)
Medical assessment (FORM 4; Appendix 7)	BSL	Birth history; past medical history, current health status; chest status; physical and sensory functioning, CP diagnosis, screen for GOR.
GMFCS (Palisano *et al.*, 1997) (FORM 5)	BSL	Gross motor skills - functional ability (5 levels).
Initial Feeding Interview (FORM 6; Appendix 8)	BSL	Recent child health; diet (child and family); carer sensitivity and responsiveness; child's feeding difficulties (in the words of the carer and using structured rated oral questionnaire); caregiver feelings about the child's feeding difficulties (overall and whilst feeding); level of priority given to the feeding difficulties; previous contact with services; carer's hopes from the training; level of support at home.
Mealtime observation schedule (FORM 7; Appendix 9)	BSL, PAR, PRT1, PRT2	Observations of child at rest; oral & pharyngeal behaviours (food & drink); child affect; carer interaction style; hygiene & use of our equipment; feeding methods (food consistency, positioning, seating, utensil, amount per mouthful, pacing, angle and speed of delivery to mouth, support for lips/jaw, management of spillage, management of food remaining, mixing food & drinks, cup kept filled.
Training Needs Summary (FORM 8; Appendix 10)	BSL, PAR, PRT1, PRT2	Identified aims for child and caregiver and carer training targets (diet, food consistency, oral desensitisation/exercises; feeding methods (food and drink), caregiver interaction style).
Goal Review (FORM 8a; Appendix 11)	BSL, PAR, PRT1, PRT2	Reasons for caregiver non-compliance
Post Advice Interview (FORM 9; Appendix 12)	PAR	Update on child health, carer emotional state, any other changes. Otherwise same as FORM 6 plus hygiene awareness questions (from FORM 1); test of knowledge; feedback on the material and equipment we gave.
Post Training Interview 1 (FORM 10; Appendix 13)	PTR1	Same as FORM 9 plus detailed feedback on the training sessions.
Post Training Interview 2 (FORM 11; Appendix 14)	PTR2	Same as FORM 9 plus questions regarding observed changes in self and child since PTR1.

Table 2-3 Summary of scales used within the tools

SCALES WITHIN TOOLS	AREAS ASSESSED
Frequency rating of feeding problems (FORMS 6,9,10,11)	Length of mealtimes; Carer availability; child food refusal; particular about food; Carer perception of child's satiety; spillage; coughing/choking; nasal regurgitation; oral regurgitation; crying; if feed in lying; if feed with head back; verbal forcing; physical forcing.
24-hour food recall (FORMS 6,9,10,11)	What, when, how much (size and number of items/bowl quantity) consistency, utensil.
Monthly food frequency (FORMS 6,9,10,11)	List of commonly consumed items separated into food categories – frequency of consumption scored daily, weekly or monthly.
Test of caregiver knowledge (FORMS 6,10,11)	Diet; positioning; & support for self-feeding; food consistency; responsiveness; hygiene.
Rating of child affect (FORM 7)	Content; complaining or uncomfortable; distressed (*occasionally/sometimes/most or all of the time*).
Rating of caregiver interaction (FORM 7)	Positive verbal proactive; negative verbal proactive; negative physical proactive; responsiveness (*never/occasionally/sometimes/mostly/always*).

Caregiver interview

Observation of feeding

Medical assessment

Figure 2.4 Photographs of data collection

2.6.2.2 Methods of data collection: reliability and validity

Methods of data collection were based on recommendations from the literature and included structured caregiver interviews, coded feeding observations and objective anthropometric measurement.

Data were collected and analysed by the same researchers, which increased the risk of a bias in the study. Reflection on the process was therefore of paramount importance throughout, and efforts were made to ensure objectivity and reliability where possible. Consistency of assessor was considered an advantage with regards to the latter.

The need for translation during interviews was a further potential risk to validity of the data. However, careful efforts were made to address this. Both the British Principal Investigator (PI) and Bangladeshi Research Assistant (RA) were present during interviews. The PI's comprehension of Bangla was reasonable in terms of the subject matter and the RA had a competent level of English. The RA asked the questions according to the agreed translation, adapting the vocabulary to local dialect and clarifying the meaning where necessary, to ensure optimum comprehension. In accordance with Berkanovic (1980, cited in Esposito, 2001), this process also ensured the language usage was socially respectful and acceptable to research subjects.

Caregivers' answers were simultaneously translated and recorded in English by the PI on the interview forms, rather than being audio-recorded and later transcribed and translated. This process avoided potential inaccuracies of translation dependent on the transcriber's level of knowledge of the research and vocabulary used (Krueger, 1993, cited in Maynard-Tucker, 2000). Instead, the researcher was able to listen to the dialogue as it took place and intervene to clarify or explain where necessary, thereby reducing threats to the validity of cross-language translation issues (Esposito, 2001). Being present in interviews also meant that nonverbal interactions, which are useful indicators of the truthfulness of the participant's responses and their feelings about the topic (Maynard-Tucker (2000) could be observed, which would not have been possible from translated transcripts. As suggested by Esposito (2001), simultaneous translation of carers' responses also allowed the PI to be actively involved and to have more control over the data collection process, ensuring a higher quality of data collection by adjusting questions and comments in response to unanticipated answers where needed (Esposito, 2001). This was useful in ensuring validity, threatened by any lack of the RA's training and skill in either the subject or methods of interviewing, which would lead to potential biasing of the respondents' answers or the collection of poor data (Maynard-Tucker, 2000). The PI's real-time understanding of the interviews was

also important in terms of knowing what advice to give at the end of the session. Audio recordings of the interviews could have been taken to be later used as a checking tool, however, it was desirable to minimize recordings during the home assessment sessions to prevent carers from feeling inhibited and therefore to ensure maximum validity of data collected. Prioritisation was instead given to the video-recording and photographing of mealtime observations, both of which were invaluable in the analysis.

Mealtime observations were recorded through photographs, in written form and on video. Although it is recognised that using videos can influence the behaviour of those being observed through 'observer effect' it was felt that in this study, videos were essential in enabling the accuracy of written recordings (through retrospective checking, and post-study inter-rater reliability-testing in order to validate the data before analysis. When caregivers were asked for feedback on being videoed, they all said it had not troubled them nor changed what they were doing. Videos were taken throughout the programme, except for during a short period of equipment failure when photographs and double-scoring were used to ensure reliability.

Quantitative assessment methods were influenced by the availability of suitable validated assessments for the client group, in addition to the availability of instrumentation and clinical expertise in the study locality. These factors necessitated assessment methods to be based on a combination of clinical observations and caregiver reports rather than using more objective methods such as videofluoroscopic assessment of the swallow function and pH testing for reflux. Further details of this are discussed in Chapter 4.

Oral ability to manage food was not assessed in a systematic fashion in this study due to predicted difficulties in providing a consistently controlled environment and the advantages of conducting observations in a naturalistic feeding situation. The latter was selected as it allowed some assessment of the dynamic between the caregiver's feeding practices and the child's ability to manage the food provided (chosen by the caregiver). Level of severity of feeding difficulty was also not defined for these reasons, as well as the fact that no standardised measure currently exists. The use of a naturalistic assessment method also provides some ecological validity to the study, as the evaluations were more closely related to the real-life feeding experience for these families.

Much of the data gathered relied on reported information, which can be affected by the psychological health of the reporter (Moore *et al*., 1988). Maternal reports on child health status have nonetheless been seen to be a very effective means of data

collection in Bangladesh (Rousham *et al.,* 1998) although under-reporting of feeding difficulties may occur, as a result of caregivers' sensitisation to their child's feeding difficulties (Reilly *et al*., 2000, p.166).

Although the use of anthropometric measurement is widely recognised as a reliable way to assess nutritional status with non-disabled populations (Waterlow *et al*., 1977; WHO Working Group, 1986), accurate anthropometric measurement is difficult to achieve with this population, due to the problems in attaining and sustaining the necessary body position (especially for length measurements) owing to body deformity and contractures. Furthermore, the interpretation of measures involving subcutaneous fat stores in this population is complicated by fat distributions differing from those in non-disabled children (Sullivan and Rosenbloom 1996; Spender *et al.,* 1988; Azcue *et al.*, 1996). Stallings *et al.* (1996) state however, that growth monitoring is possible using measures for weight, subcutaneous fat and an alternative measurement of length. Alternative measures of length recommended in the literature include armspan, arm length and tibia length (Yousafzai *et al.*, 2003b; Stevenson *et al*., 2006). Sullivan *et al*. (2002) found weight and upper arm circumference measurements easy to perform and good indicators of nutritional status in their study. Sibling measures are often taken as a comparator and in order to establish a proxy measure for height when assessing the nutritional status of children with disabilities, due to the nutritional variation that can occur between families as a result of differing parenting skills as well as socio-economic factors (Socrates *et al.*,1997; Yousafzai *et al.*, 2003). In this study, national references established for Bangladeshis living in urban areas using data from the Child and Mother Nutrition Survey of Bangladesh 2005, were used (Bangladesh Bureau of Statistics, 2005). This was done partly to reduce the time spent at home visits (average 2-3 hours), which was already burdensome for the families and partly because there was a lack of available siblings for matching. The 'control' data in the study were therefore used exclusively for the baseline comparison of overall nutritional status.

Data pertaining to nutritional intake (Brown *et al*., 1982; 1985), health (Briscoe, 1979) and growth (Brown *et al.,* 1982; 1985), were potentially subject to seasonal variation. Certain foods, especially fruits, are only available for brief periods of the year and the price of other foods, even staples, varies from season to season, depending on availability. Likewise, levels of infection are known to increase in the monsoon season, which in turn impact on child nutritional status (Rousham and Mascie-Taylor, 1995). Specific questions were added to the interviews in order to take these issues into account and the use of weight-for-age rather than weight-for-height measures were

considered advantageous as the former is reputedly less sensitive to seasonal variation (Brown *et al.*, 1982).

2.6.2.3 Tools: reliability and validity

Where possible, validated and published assessments were used. These included the following:

- The multidimensional measure of poverty, the Poverty Mapping Questionnaire (Bhuiya *et al*., 2007; Appendix 5) which was designed to assess poverty in the rural populations of Bangladesh. Due to the differences between rural and urban lifestyles, some small adaptations to the questionnaire were necessary, which did not affect the overall scoring.
- The Self-Reporting Questionnaire 20 items (SRQ,20 item yes/no version; Harding *et al*., 1980; Appendix 6), for assessing mental well-being. Based on the General Health Questionnaire, the SRQ20 is a recognised measure of mental health (psychiatric as well as minor behavioural illness) particularly appropriate for use in developing countries (Harpham *et al*., 2003, 2005).
- The Gross Motor Function Classification System (GMFCS) (Palisano *et al*., 1997), which is fast becoming a popular tool in global CP healthcare and research (Samson-Fang *et al*., 2002; Houlihan *et al*., 2004; Morris and Bartlett, 2004), used to establish the children's level of physical functioning.

Some more instrumental tools of data measurement were avoided not only because the equipment and expertise were unavailable (eg. Ph-testing for GOR) but also because, in some instances, their reliability is still in question (eg. the use of oxygen saturation monitoring (Morgan *et al*., 2008) and cervical auscultation (Leslie *et al.*, 2004) to aid the assessment of swallow function). With regards to dietary information, the need for low-technology assessment methods suitable for the home environment which did not require a heavy time burden again led to this information being obtained through interview rather than through detailed measuring.

Where it was necessary to design new tools, these were based on information from research, schedules and scales developed and validated by other clinicians and/or researchers, as follows:

- The socio-demographic interview (FORM 1; Appendix 4). This was developed locally, in order achieve greater validity for use in this environment.
- The medical assessment schedule (FORM 4; Appendix 7). This was designed with the help of doctors working in two child development centres in Dhaka in order to obtain medical information that was associated specifically with this client group,

rather than use a standardised tool such as the CHQ (Landgraf and Ware, 2003) which is less specific.

- Caregiver feeding interviews (FORMS 6, 9, 10, 11; Appendices 8, 12-14). These included questions to assess responsiveness, sensitivity and interaction style which were adapted from an interview used in the Bangladesh MINIMAT maternal-infant interaction study 2003-4 (Frith *et al.*, 2004). They also included questions on dietary intake (child and family) based on the Food Frequency Questionnaire (FFQ) which has been adapted and validated internationally (Torheim *et al*., 2001; Shu *et al*., 2004) including in Bangladesh (Chen *et al*., 2004). The food frequency questionnaire for the study was developed using information gathered during the pilot period, on Bangladeshi diet and especially that of children with feeding difficulties. The questionnaire elicited information on food frequency and quantity (using portion size) over a 24 hour period and frequency alone over a monthly period. (This information was not used to calculate exact nutritional intake but more as an indication of diet and overall quantities of food intake).
- The Mealtime Observation Schedule (FORM 7; Appendix 9). This was based on a combination of clinical assessment guidelines (Arvedson and Brodsky, 2002; Reilly *et al.,* 2000, pp.153-170; Winstock,1994; McCurtin 1997; Sullivan and Rosenbloom, 1996), information from research studies (Waterman *et al*., 1992; Loughlin and Lefton-Greif, 1994; Trier and Thomas, 1998)**,** evaluated clinical assessments and reviews thereof (Kenny *et al*., 1989; Reilly *et al*., 1995; Wolf & Glass, 1992) and tools used in behavioural research (Moore *et al*., 2005; Kochanska and Aksan, 2004). (Further details on the Mealtime Observation Schedule are given below).

Content validity was further addressed by seeking feedback from clinical experts on the suitability and the comprehensiveness of the tools developed for the study. Face validity was assessed during piloting of the tools in an inpatient rehabilitation unit for children with physical disabilities, with the help of a volunteer research assistant. Attention was paid to questions that caregivers did not understand, answers that appeared biased and the ability with which caregivers were able to rate using rating scales of differing numbers of options. Additional piloting, and pre-study reliability-testing of the Mealtime Observation Schedule (FORM 7; Appendix 9) were performed with two Speech & Language Therapists (SLTs) in Sri Lanka, which led to further modifications of the form. Pre and mid-study reliability testing of the same tool were carried out between the principal investigator (PI) and the research assistant (RA) and post-study reliability was performed with a visiting SLT from Australia, in the role of 'external auditor'. The outcomes of the pre and post-study reliability testing are reported in section 2.6.2.4 below. Criterion validity of the Mealtime Observation

Schedule was not possible as the approach to scoring was novel and therefore an appropriate comparator was not available. Extensive pre-study practice and reliability-testing were applied to taking anthropometric measurements, following standard procedures and using the methods of armspan measurement recommended by Yousafzai *et al*. (2003b). During the study, three recordings were taken for mid-upper-arm circumference and demi-armspan measurements. (The mean of these was used in the analysis of the results). Electronic scales were used to assess weight, which were periodically checked for accuracy.

From the outset, the measures regarded as containing the greatest level of internal validity were those which involved objective measurement or rated researcher observation. These therefore included the anthropometric measurements and mealtime observations.

Accuracy of caregiver reports was potentially confounded by the memory load required by some of the questions, such as monthly food recall. Using the 24hr recall (which requires a much lower memory load) helped to see where the estimate given for monthly intake may have been inaccurate.

2.6.2.4 Tools: details of the Mealtime Observation Schedule

The Mealtime Observation Schedule (FORM 7) was a key tool for evaluating the outcomes of this study, and is therefore described here in detail, as follows.

Apart from information gained during interviews, it was necessary to observe feeding in order to assist in the identification of individual training goals for caregivers. Few standardised observation tools are available although several informal observation schedules and scales have been developed. The most important of these are: The SOMA: Schedule for Oral Motor Assessment (Reilly *et al*., 2000), The Multidisciplinary Feeding Profile (Kenny *et al*., 1989), Dysphagia Complexity Index (Selley *et al*., 2001), Classification of Eating Impairments (Gisel and Alphonce, 1995). For the purposes of the study however, it was felt that a tool should be developed especially, in order to meet the needs of the clinical and cultural context and which could be a prototype for future use within the service. Such a tool would need to be adapted for clinicians with basic training, thorough enough to obtain a good baseline and provide enough information to identify training goals but short enough to be completed under time pressure. The assessment designed for this study is an assessment of function, which, in accordance with the ecological model (Bronfenbrenner, 1979) reflects the interdependence between caregiver practices and the child's feeding ability. It was

believed that this would provide a better basis on which to identify carers' training needs, and could be used as a valid tool for measuring outcomes with regards to change in caregiver feeding practices post intervention and the possible impact that is having on the child's ability to manage food and drink. In this regard the tool is novel. It differs from the tools used by previous researchers in the way that it records and evaluates caregiver feeding methods and interaction style at the same time as the child's feeding skills and affect, during a typical mealtime.

The breadth of caregiver assessment (observations of caregiver interaction as well as the practical aspects of feeding manner that can impact on nutritional intake, risk of aspiration and child well-being during feeding) complies with the principles of 'responsive feeding' outlined by Engle *et al*. (2000), which (as outlined in Chapter 1) include sensitivity to the child's psychomotor abilities for self-feeding and the use of responsive and active feeding methods. The principles of responsive feeding are used as the framework for cutting-edge nutrition programmes for carers of non-disabled children and studies have shown successful increases in child cooperation and nutritional intake by focusing on the caregiver interaction style during feeding (Moore *et al.*, 2005; Blissett and Harris, 2002). Attention to caregiver interaction is equally relevant, if not more so, to the feeding of disabled children, where positive proactive and responsive caregiver behaviours are particularly at risk (see Chapter 1, section 1.6). According to Black (1999), attention to the caregiver-child interaction during feeding is a 'critical component of the evaluation of feeding problems'. It is also of particular relevance when working with caregivers whose culture promotes controlling feeding methods as is the case in Bangladesh (see Chapter 1, section 1.6). Adapted from the assessment schedule developed by Moore *et al*. (2005), observations of caregiver interactions in this assessment tool are separated into 'proactive' behaviours (ie. behaviours that encourage or force the child to eat) and 'responsiveness' to the child's cues. Proactiveness is caregiver-driven, whereas responsiveness is child-driven. Proactiveness is broken down into positive and negative, verbal and physical. In this study, caregiver interactions recorded were positive verbal proactiveness (verbal encouragement) and negative verbal or negative physical proactiveness (verbal or physical forcing).

Scoring system

The assessment requires observation and scoring of the whole mealtime. (Meals were occasionally stopped if the child became particularly upset or if the feeding method appeared particularly harmful). The tool is laid out as a checklist of behaviours (child and caregiver) which are ticked as they are observed, or rated on a scale. The food eaten, length of the mealtime and whether the carer believed the meal to be 'typical' are also recorded at the end of the observation. Details of the rating scales contained within the schedule are as follows:

- Child Feeding behaviours:
  Abnormal behaviours observed are scored as occurring *occasionally* (1-3 times or <10% of the mealtime) or *frequently* (regularly or consistently throughout the meal). No score is given for an absence of the behaviour. The scale is a modification of the rating scale developed by Gisel and Alphonce (1995).
- Caregiver feeding practices:
  Caregiver feeding practices were originally rated on a scale of appropriateness (1-3) but the subjectivity of this system affected inter-rater reliability and so the scale was replaced with a record of what was observed rather than a judgement of clinical appropriateness. This therefore became a written record of the mealtime observations, to supplement videos and photographs.
- Caregiver interaction style:
  The timed sampling scoring method (as used in the 2004 ICDDR,B feeding project, Moore *et al.* (2005), was simplified into a rating scale of frequency (*never, occasionally* (<25% of the time), *sometimes* (approximately 50% of the time), *mostly* (approximately 75% of the time) *and always*, based on the researcher's overall observation.

As the Mealtime Observation Schedule provided an objective record of events, an additional tool (FORM 8; Appendix 10) was required to record the areas of need, based on how the child reacted to their caregiver's feeding methods, and from which individual caregiver training goals could be set and reviewed throughout the programme. The scoring of goal attainment also provided an additional outcome measure, based on the principles of Goal Attainment Scaling (Kiresuk and Sherman, 1968). Goal modification would depend on changes in caregiver behaviour, child feeding skills and the interaction between these. This review and update process required the employment of clinical judgement based on the agreed principles of safe and responsive feeding recognised by practitioners specialising in this field, as outlined above.

Reliability

As mentioned previously, reliability was checked pre-study and mid-study by double-scoring during live assessments and checking all scores retrospectively, against video footage (PI and RA). Pre-study testing was conducted on five cases, for which agreement reached 84% or above on all scores except for child affect (40%), responsiveness (40%) and amount per mouthful (drinks) (22%). The latter two variables were not used in the study analysis. Statistical analysis of agreement was not carried out pre-study, due to the small number of cases observed, however the percentage agreement indicated an adequate level of reliability for use of the tool within the study. The results were later combined with the post-study tests for statistical analysis and are summarised below. (See Appendix 20 for details).

Post-study retrospective reliability testing was carried out by an independent expert for all sections except interaction style. This was completed by the study RA as knowledge of Bangla was required. A random selection of five score sheets from C1 (Baseline) and five from C2 (PTR1) were used. Records were selected from Baseline and PTR1 in order to evaluate scoring which occurred at different times during the study. Some variables were difficult or impossible to observe accurately using videos alone and were therefore inappropriate for reliability testing. These included oral and pharyngeal behaviours, food and drink consistency, verbal preparation of child for feeding, mixing of food with drinks, keeping the drinking cup well-filled. Other variables which were excluded were head rotation and tilting, the angle of the spoon (delivered facing forwards or sideways; withdrawn straight or over top lip) and consistency of drinks, as they were considered the least informative variables and ones that could be eliminated from the assessment schedule.

Reliability using Cohen's Kappa (Cohen, 1960) was calculated on the remaining variables, some of which were not used as outcome measures but were important in assigning appropriate training objectives.

The scores for responsiveness and negative verbal proactiveness revealed these to be the areas of least agreement. The scoring system for negative verbal proactiveness, although achieving a Kappa score of only 0.27 was nonetheless used in the study analysis, as the percentage agreement was 73%. The low agreement using the Kappa test was likely to be due to the homogeneity of the client group, resulting in a high number of the same score being given for this variable during the feeding observation. This was then 'corrected for' by the Kappa test which interprets such results as having possibly occurred by chance. The measure for responsiveness was not analysed

however. Instead, responsiveness of feeding manner was measured according to appropriateness of amount of food given per mouthful and speed of feeding. (Overall responsiveness was measured through the number of training targets identified).

Reliability for the other variables was mostly good or excellent, according to the classifications of Fleiss (1981). Nine of the eighteen variables analysed achieved agreement scores of >0.75 (excellent), four achieved a score of 0.60-0.75 (good) and three achieved a score of 0.40-0.60 (fair).

2.7 Intervention: design, content, methods and materials

Initial advice was given to carers immediately after the baseline assessment and focused on the key caregiver feeding practices which were compromising safe and responsive feeding and included some degree of demonstration.

Group training comprised six sessions held fortnightly at the Shishu Hospital, and was conducted by the Developmental Therapists working in the unit, who received specific training and were supervised throughout. The overall programme design was arrived at through consultation with mothers already receiving services for their children in the unit and local organisations running nutrition programmes for the mothers of non-disabled children. Information from these sources suggested that a programme should run for no less than two months, comprise at least four sessions and would achieve a higher level of attendance if held fortnightly rather than weekly. Although nutrition training programmes are usually more intensive (Roy *et al.,* 2005), this was not possible as an outpatient service. The group size was decided upon in discussion with the therapists performing the training taking into consideration the location, the number of therapists available to assist and the number of mothers therefore that could feasibly be supervised during the practical part of the session. A maximum number of five child-caregiver pairs was agreed on.

The training content and methods (see Appendix 16) were influenced by recommendations in the literature, by reports written on training programmes conducted in developing countries, including Bangladesh, and from interviews with caregivers during the pilot stage (see table 2-4 below). The use of video material, a recommended training method (Black, Cureton & Brenson-Howard, 1999) was particularly important in the study. Specific information on recipes designed for malnourished non-disabled children was obtained from the International Centre for Diarrhoeal Research, Bangladesh (ICDDR,B) and example daily diet plans were compiled in consultation with the nutritionist at the Shishu Hospital.

Improving dietary intake through caregiver education on nutrition was supported by evidence from a study by Nahikian-Nelms (1997) who found positive correlations between nutrition knowledge and caregiver behaviour at mealtimes, nutrition knowledge and attitudes and attitudes and caregiver behaviour. Although nutrition education alone was successful in their study, Roy *et al*. (2007) recommend the dual approach of nutritional education as well as providing an energy-dense protein rich food supplement. A supplement was not provided in the current study however, for reasons of cost and impact of non-sustainability post study. Ideas on how to promote

responsiveness in caregivers are outlined by Satter (1990), Benoit *et al*. (2001), Horowitz *et al.* (2001) and Pelto *et al*. (2003); the number of learning items to present to carers is recommended by Chadwick *et al.* (2002) and Aboud (2004). Organisations working locally, such as Concern Bangladesh, and Plan Bangladesh, recommend the use of practice, problem-solving and support as key training methods (Aboud, 2004). This is demonstrated in the 'Hearth' approach (Sternin *et al*., 1998) used by Concern Bangladesh, whereby mothers get together in groups to cook food using the methods of food preparation and hygiene they have been taught. Concern also advocates the use of skilled peers in training, following the principles of the Positive Deviance approach to health training (Marsh *et al.,* 2004). The use of discussion is also recommended as a significant teaching/learning tool in the Hearth Model (Sternin *et al*., 1998) and by others (Penny *et al.*, 2005). The involvement of the whole family is also suggested (Socrates *et al*., 2000). Becker & Rosenstock (1984) and Brumfitt (1999) outline various factors which increase the effectiveness of an intervention programme. These include limiting the number and complexity of instructions, the cost implications of the advice and the disruption that will be caused to daily life. They also recommend giving visual materials to take home and to encourage the support from a family member. Information was also obtained from caregivers, during piloting, on local cooking and feeding practices, caregiver priorities and stresses, and knowledge on nutrition, hygiene, cerebral palsy, the consequences of feeding difficulties and malnutrition, to help pitch the content of the training.

A summary of the training objectives, and their rationales for selection are illustrated in table 2-4 below.

Table 2-4 Summary of training objectives and rationales

Training Objective		Rationale	Related child outcomes	Reference
1	Introduce high calorie, balanced diet, given in small amounts frequently.	Increase nutritional intake through improved diet and increased quantity of food consumed.	Weight gain.	Gisel & Alphonce (1995) Thommessen *et al.* (1991b, 1991c) Reilly *et al.* (1996) Socrates *et al.* (2000) Trier & Thomas (1998) Gisel & Patrick (1988) Roy *et al.* (2005)
2	Adapt food consistency as appropriate.	Reduce risks of aspiration by enabling more effective oral and pharyngeal management of food. Increase nutritional intake through reduced effort, increased calorie density of food and encouragement of more mature oral feeding patterns.	Reduction in chest-related illness. Improved oral feeding skills. Increased child cooperation. Weight gain.	Gisel *et al.* (1995) Gisel & Patrick (1988) Patrick & Gisel (1990) Croft (1992), Rogers *et al.* (1994) Trier & Thomas (1998) Thommessen *et al*. (1991c)
3	Use appropriate utensils.	Reduce risks of aspiration by enabling more effective oral and pharyngeal management of food. Encourage more mature feeding patterns and Increase nutritional intake.	Reduction in chest-related illness. Reduced child distress. Increased child cooperation. Weight gain.	Trier & Thomas (1998)
4	Facilitate appropriate trunk & head position during feeding.	Decrease risks of aspiration Facilitates maximisation of physical abilities.	Reduction in chest-related illness. Maximisation of self-feeding skills. Increased child cooperation. Weight gain.	Trier & Thomas (1998) Waterman *et al*. (1992) Larnert & Ekberg (1995) Selley *et al.* (2001) Gisel *et al*. (2003) West & Redstone (2004)
5	Provide support for jaw stability where necessary.	Reduce spillage and assist chewing /overall oral management of the food.	Improved oral feeding skills. Weight gain.	Haberfellner *et al*. (2001) Selley *et al.* (2001)

Training Objective		Rationale	Related child outcomes	Reference
6	Foster self-feeding skills.	Increase nutritional intake through increasing desire to eat and ability to eat independently.	Weight gain.	Waterman *et al*. (1992)
7	Carry out oral desensitisation and oral motor exercises (the latter on moderately affected children only).	Enhance capacity for chewing and therefore to take more solid food, which has greater calorie density. Reduce food spillage which in turn increases the quantity of food intake.	Weight gain.	Shapiro *et al*. (1986) Sisson & Dixon (1986) Gisel *et al.* (1995, 1996, 2000) Trier & Thomas (1998) Troughton & Hill (2001)
8	Use sensitive, proactive and responsive feeding methods (including hygienic cooking and feeding practices).	Decrease risks of aspiration, increase nutritional intake and decrease distress to child through enabling the more effective management of food. Increase nutritional intake through physically facilitating feeding, and by increasing child's desire to eat and their enjoyment of mealtimes. Reduce risk of food contamination through increased hygiene.	Reduction in chest-related illness Weight gain Reduced risk of diarrhoeal disease Decreased child distress Increased child cooperation	Engle & Zeitlin (1996) Engle (2000) Moore *et al*. (2005) Satter (1990) Horowitz *et al*. (2001) Selley *et al.* (2001) Pelto (2000) Hurley *et al.* (2008)

In addition, medical treatment for gastro-oesophageal reflux was provided where required, with the aim of reducing pain during feeding and potential lung damage caused by aspirated refluxed materials, thereby enabling more effective feeding and reducing chest-related illness (Trier and Thomas, 1998; Gisel *et al.*, 2003). Treatment for epilepsy was also available as well as referral to counselling for the caregivers.

To avoid overload for the carer trainees, a careful selection of training content was made for the group training curriculum. Additional interventions such as 'messy play' were taught to the individual caregivers of children for whom they would be particularly useful.

Although weight gain is the desired outcome of many the many training objectives, the degree to which weight gain is possible will always be limited by the children's underlying neurological impairment in oral motor skills. As mentioned in Chapter 1, it is believed by many researchers that severe oromotor difficulties prevent adequate nutritional intake (Johnson and Deitz, 1985; Gisel and Patrick, 1988; Sullivan *et al.*, 2000; Troughton and Hill, 2001). Hence the emphasis in well-resourced countries on alternative feeding.

In this study, each training session was divided into a formal educational part and a practical part involving supervised feeding, thereby providing general information relevant to all of the caregivers as well as tailored information relevant to the specific needs of each child-caregiver pair. The former included training on diet and the principles of safe and responsive feeding practices (including feeding manner and caregiver interaction). The groups were divided into two subgroups for training on oral-facial desensitisation and exercises (one for children with increased muscle tone and one for children whose muscle tone was reduced). Caregivers were then given individual training on the specifics of positioning, food consistency, specific feeding techniques and the appropriate utensils for their child. Teaching methods included traditional pedagogy, discussion, experiential activities, and the use of visual aids including photographs, pictorial instruction sheets, videos of other mothers, and a 20-minute video drama written especially for the programme. The video drama is a 25-minute film about a boy with cerebral palsy living in a remote village of Bangladesh, who develops a chest infection as a result of his feeding difficulties and the mother's feeding methods. The boy is visited by a doctor who sends out a community health worker who teaches the parents about all the aspects of diet and feeding that are covered in the study training group sessions and includes demonstration of the techniques taught. The parents in the film use the new methods and the child recovers from his illness. The film was written, performed and filmed using a local theatre group, a child with cerebral palsy, a volunteer film-maker and the Principal Investigator (see supplementary material attached).

Formal education: diet

Supervised feeding

Filming of the video drama

Figure 2.5 Photographs of training and training materials

Sessions were facilitated by two pairs of Developmental Therapists working in the unit, who had undergone training themselves in conducting the six-session training programme. Each pair ran groups running on different days and during training of the C2 cohort was joined, for one session, by an 'expert' mother from C1, in the role of peer educator, who was there to answer questions from the other carers regarding carry-over into the home and what impacts she had observed from the training. The PI and RA were present at all training sessions to ensure quality a consistency of training and to make observations of the children and carers. More than one caregiver of the same child was invited to attend the sessions if they were also involved in feeding the child at home. Other family members and friends were always welcome and were invited to attend the last session in particular. Pictorial information was designed using a local artist and adapted from illustrations used in training manuals by local organisations in Bangladesh (Prothibondi Foundation), India (Indian Institute of Cerebral Palsy, Calcutta) and Sri Lanka (Special Seating Service, Ragama Hospital).

The equipment and materials given to the caregivers were considered to be part of the overall intervention. These included specially designed seats made of low cost materials, using the techniques of Appropriate Paper-based Technology (APT; Packer, 1995) to facilitate appropriate posture during feeding and appropriately sized cups, spoons and toothbrushes (see figure 2.9 below). The children were also given de-worming syrup to ensure maximum benefit from nutritional intake. (As the children largely lacked the mobility to move around the floor, they were considered unlikely to have worms before entering the programme and therefore taking the syrup was unlikely to confound the results). The caregivers were given two laminated pictorial information sheets to take home. The first was a diet sheet outlining daily diet plans for children of different ages and instructions for high calorie recipes. The second was a sheet to remind caregivers about positioning and feeding methods. The information on the diet sheet was compiled in consultation with the Clinical Sciences Division at the ICDDR,B (Institute for Diarrhoeal Disease Research, Bangladesh) and the Children's Nutrition Unit, Shishu Hospital and based on recommendations for malnourished non-disabled children (Khanum *et al.*, 1994). Recommendations are categorised according to age rather than height/age, because this is a simple sustainable system for the hospital to continue to use in the future.

Adapted APT seat

Cups, spoon, toothbrush, advice sheets

Figure 2.6 Equipment given to participants

2.8 Data analysis

2.8.1 Quantitative data

Child and caregiver change was assessed by comparing the repeated scores from the quantitative measures and information from qualitative questioning, taken at the different assessment and review points (see figure 2.2). Caregiver behaviour change was also evaluated against individual training targets. This measured caregiver competence in the specific aspects of feeding identified as a training need for that child-caregiver pair. These data were also used to identify which areas of training were most / least complied with following advice only versus advice plus training.

To evaluate the impact of the whole programme (*advice plus training*), data were analysed from those C1 and C2 participants who completed the training programme and were reviewed twice, comparing the baseline assessment (BSL) with the post-training reviews (PTR1 and PTR2). Data from the C2 cohort were used to evaluate the impact of *advice only*, comparing the baseline assessment with a post-advice review (PAR) following a non-intervention phase. This group includes those C2 participants who went on to attend the training sessions and those who declined or were unable to attend. This group is called C2A.

It was decided to combine the results for C1 and C2 for the purposes of analysis as few differences were expected in the results of the two cohorts. Despite being recruited from different areas of the city, the majority in each cohort were living in slum areas and accessing a similar level of community services. It was also believed that the extra contact C2 carers received from the researchers at their post-advice review as well as additional practice time during their non-intervention phase would be largely 'superseded' by subsequent learning that would be achieved from attending the training sessions. Any significant differences in the results at baseline or the outcomes following intervention are reported where they occur and discussed in Chapter 4. Tables illustrating the C1 and C2 data separately are in Appendix 22.

For comparison of nutritional status with children from other studies at baseline, anthropometric data were analysed using the WHO 2006 Growth Reference Standards and the National Center for Health Statistics (NCHS) references (Hamill *et al.,* 1979). The anthropometric outcomes were analysed using the British 1990 growth reference standards, adopting the LMS method (Cole *et al*., 1998) and the CP growth reference standards developed by Stevenson *et al*. (2006). The British 1990 growth reference standards were chosen over other recognized standards as the age range they cover permitted the inclusion of data from all of the study children. The outcome data were

analysed using standards for the non-disabled population as well as the CP population in order to compare any differences.

Although there is a debate as to the appropriateness of using international standards, which perforce are based on better-nourished children growing in a well-resourced environment, the recognised advantage is in the subsequent identification of children at risk of poor health from malnutrition (Kow *et al*., 1991). It also allows for comparison with the results from other studies.

Statistical analysis was conducted following a planned comparison of the data collected at the different time points using the computer package 'SPSS for Windows' (version 15.0). An initial test was applied to identify overall significance across the time points. If significance was achieved overall, a two-level test evaluating change between BSL and PTR1, BSL and PTR2 was applied in order to establish where changed had occurred.

When the data met the assumptions required for the use of parametric tests, a one-factor within-subjects analysis of variance (ANOVA) and the Paired Samples T-test were used. For non-parametric analysis of the data, the Friedman Test followed by the Wilcoxon Signed Ranks Test were used for multiple category data, and the Cochran Test followed by the McNemar Test were used for dichotomous data.

A summary of the methods of analysis for each variable can be found in appendix 21.

2.8.2 Qualitative data

Analysis of the caregiver responses obtained from eight open-ended questions was informed by the methods used in Grounded Theory (Glaser and Strauss, 1967) and recommended by (Corbin and Strauss 1990, cited in Creswell, 1998, p150). This was a five stage process, as follows.

Stage 1

Using a constant comparative approach, the answers to each question with a similar meaning were grouped together to form a list of representative answers. This was done by the PI and RA together.

Stage 2

These answers were then grouped, using the same process, to form categories or themes. This was done by the PI and the RA independently.

Step 3

The themes identified by the PI and RA independently, with their underlying subcategories (representative answers), were compared. Adjustments were made in agreement with one another.

Step 4

The PI and an independent researcher looked at the list of themes from the eight questions and rationalised them into one list. This was done separately.

Step 5

The PI and independent researcher compared their final list of themes and agreed amendments.

The following chapter gives a description of the participants at baseline followed by an analysis of the results in terms of changes in the children, the caregivers and caregiver feeding practices following intervention.

Chapter 3

Results

3 Results

This chapter reports the results of the study. Overall, these demonstrate that even in the most deprived circumstances, and regardless of carer education or psychological well-being, a minimum of four caregiver training sessions will, in the majority of cases, have a significant impact on nutritional intake, chest health and the experience of mealtimes for the child and their caregiver. Better outcomes are associated with early intervention.

The chapter is divided into seven sections. The first gives a description of the participants, including biodata and information on their socioeconomic circumstances and feeding behaviours, at baseline. Sections 2-4 examine changes in the children, the caregivers and changes in caregiver feeding practices following intervention. Each of these sections gives a detailed analysis of the data and periodic comments to aid the reader's understanding, outlines factors affecting compliance and provides a summary of the results. Section 5 explores the clinical effectiveness of the training and explores the relationship between changes in caregiver feeding practices and child outcomes. Section 6 summarises caregiver feedback on the programme and section 7 provides audiovisual illustrations of the results.

The outcomes for the children and caregivers are reported first as these were the target of the intervention. The effectiveness of the training is reported second. The methods of data analysis are described in Chapter 2 (pp. 93-95).

For ease of comparison and to avoid repetition, the results illustrating the impact of *advice plus training* and *advice only* are reported in sequence under each outcome heading. Cohorts C1 and C2 were similar at baseline, and their results are combined for statistical analysis. Where differences emerged, these are reported in the relevant results section and discussed in Chapter 4 (section 4.4.3). A detailed comparison of the C1 and C2 results is provided in appendix 20.

Data collected are reported in three main sections relating to:

1. Outcomes for the child (objective measures, observations, and qualitative data)
2. Outcomes for the caregiver (observations and qualitative data)
3. Training outcomes (observations, quantitative and qualitative data from caregiver interviews)

On occasion, data collected from a review session were incomplete due to child sickness preventing observation of feeding or lack of time to complete interview

questions. It was not always possible to return to a house to complete the assessment. Where that occurred, the *n* value is given in the table summarising the relevant data.

3.1 Participant information

3.1.1 Attendance

C1 **April 2005** **-Feb 2006** 10 months	**Baseline (BSL)** Initial assessment & advice	**Training groups** 2 1/2 months	**Review 1 (PTR1)** 1st post-training review	**No input** 4-5 months	**Review 2 (PTR2)** 2nd post-training review
	n=16	*n*=13	*n*=11		*n*=10

C2 **July 2005** **-Sep 2006** 14 months	**Baseline (BSL)** Initial assessment & advice	**No input** 3-4 months	**Post-advice Review (PAR)** Post advice review & advice reiterated	**Training Groups** 2 1/2 months	**Review 1 (PTR1)** 1st post-training review	**No input** 4-6 months	**Review 2 (PTR2)** 2nd post-training review
	n=21		*n*=20	*n*=15	*n*=13		*n*=12

Figure 3.1 Study design and attendance

Thirty-seven participant pairs were recruited to the study, 13 of whom dropped out at various stages. The main reason was due to the family moving away (usually back to the village due to financial difficulties; *n*=7). This phenomenon has been cited by other researchers working in Bangladesh as causing great difficulties in maintaining contact with families from slum settlements in Dhaka city (Khanum *et al.*, 1998). Other reasons included lack of caregiver motivation or time (*n*=3), caregiver sickness (*n=1*), child sickness (*n*=2).

Of the 28 who attended the training groups (C1 and C2), 6 were reviewed only once, at either PTR1 or PTR2 for the reasons mentioned above or due to difficulty for the researcher to access the home environment due to floods and political unrest. Five of the C2 pairs did not continue onto training having been seen for two advice sessions only (BSL and PAR).

Thus, data analysis to assess the impact of *advice plus training* was carried out on 10 pairs from C1 and 12 pairs from C2 (all of whom were reviewed twice). Analysis to

assess the impact of *advice only* was carried out on 20 C2 pairs (5 of whom declined further training), who are referred to as C2A.

The average number of training sessions attended by caregivers in C1 and C2 was very similar (C1: 4.8 (*SD* 1.55); C2: 4.7 (*SD* 1.37)). 21 of the 28 participant pairs who attended the training, attended four or more of the six sessions. The minimum attendance at groups was two sessions.

3.1.2 The children at baseline

This section includes baseline information on the children's biodata, nutritional status, respiratory health and feeding skills. As the child-caregivers pairs in the study were likely to be representative of the population of children with moderate-severe cerebral palsy and their caregivers living in poor areas of Dhaka city, the data provides a general profile of this group. This section also It also uses these data to make a baseline comparison of the children in the two cohorts, including those C2 children who dropped out after the post-advice review (PAR).

3.1.2.1 **Biodata** (Biodata form)

The mean age of those initially enrolled in the study (*N*=37) was 47.5 months (3.96 years) (*SD* 27.26). The gender mix was equally split (M: 18; F: 19) and the majority had severe spastic quadriplegia with 89% rated at level IV or V (scale I-V) on the Gross Motor Function Classification System (Palisano *et al.*, 1997).

3.1.2.2 **Nutritional status** (Anthropometric measurement and FORM 3)

The mean weight-for-age *z*-score (WAZ), height-for-age *Z-score* (HAZ) and weight-for-height *z-score* (WHZ) of the children of <5 years of age, using the WHO growth standards (2006) ((WHO)) were -3.47 (*SD* 1.25), -2.46 (*SD* 1.47) and -3.07 (*SD* 1.44) respectively, compared with national figures for children of <5 years living in urban Bangladesh of -1.40 *(SD* 1.21), -1.49 (*SD* 1.52) and -0.80 (*SD* 1.29) (Bangladesh Bureau of Statistics, 2005). The mean mid-upper-arm circumference (MUAC) of the study children (<5 years) was 14.7cm (*SD* 1.54) compared with 14.6cm (*SD* 13).

An assessment of the nutritional status of the study children who were aged >2years, using CP growth charts ((CP 2006)) developed in the USA (Stevenson *et al*., 2006) from a population of children aged 2-19 years with moderate-severe CP (*N*=273), some of whom were likely to be suffering from acute or chronic malnutrition and growth hormone deficiency, revealed baseline scores for WAZ of -2.60 (*SD* 1.70) and MUACZ of -0.63 (*SD* 0.77).

Mean daily food (semi-solid consistencies) and fluid intake were 841.1ml (*SD* 531.8) and 201.8ml (*SD* 178.9) respectively. These measures are an estimate. They do not account for food and fluid lost through vomiting or spillage or for solid food intake (such as bananas) which could not be calculated in millilitres. Nonetheless, the levels of intake which comprised a predominantly carbohydrate and milk-based diet, suggest a risk of significant undernutrition and dehydration.

The estimated energy requirement for malnourished children with CP aged 3-10 years is 776.55-782.25 kcal per day (Sullivan, 1996, p.73). In this case, using the mean daily intake of the study children (806ml), they would need to consume food that contained an energy density of approximately 100Kcals per 100ml in order to meet their daily requirements, for which, supplementation is required. In terms of the requirements for fluid intake, most sources recommend a minimum of 1000ml per day (Forrester, 2009), which is five times the mean fluid intake of the study children (based on fluids absorbed from drinks only).

3.1.2.3 **Health** (FORMS 2, 3, 7)

39% of the study children had been sick in the two weeks prior to the first interview and in 62% of the children, chest-related illnesses were reported to occur more than once every three months. 68% were reported to have a generally negative mood.

3.1.2.4 **The 'feeding experience'** (FORMS 3 and 7)

Mealtimes were an uncomfortable experience for the majority, with 65% reported to be distressed some or all of the time. Discomfort or distress were observed by the researchers in 57% of cases during the first assessed mealtime. 84% of the children were reported to refuse their food (some or all of the time) and 70% were reported to be fussy eaters.

3.1.2.5 **Feeding skills** (FORMS 3 and 7)

Observations showed the majority of the children to be in transition between *sucking* and *munching* their food (the first two stages in the development of oral feeding skills) and only one child showed any chewing skills (which usually emerge at 8-10 months; Bronner *et al*.,1999) . Marked oral spillage was reported to occur in 81% of the children and observed in 76%. Signs indicating a risk of aspiration during feeding (*pharyngeal signs*) were observed in 97% of the children at the first assessed mealtime, occurring frequently in 65% of those. 88% of caregivers reported coughing during feeding; 35%

said it occurred all/most of the time. None of the children were involved in self-feeding to any degree.

3.1.2.6 Comparison of the children

Key features of the children whose outcomes are reported in this chapter are illustrated in the table below.

Table 3-1 Comparison of the children at baseline

	C1 (*n*=10) *Advice plus training*	**C2 training** (*n*=12) *Advice(x2) plus training*	**C2 drop-out** (*n*=8) *Advice only*
Mean age	52.2m (4.4 yrs) *SD 35.66*	40.1m (3.3yrs) *SD 14.65*	42.4m (3.5yrs) *SD 20.38*
Gender	M: 3 (30%) F: 7 (70%)	M: 5 (42%) F: 7 (58%)	M: 5 (63%); F: 3 (38%)
Type of CP Spastic	8 (80%)	8 (67%)	6 (75%)
Hypotonic	1 (10%)	2 (17%)	0
Athetoid	0	1 (8%)	1 (13%)
Mixed	1 (10%)	0	1 (13%)
Severity of CP level III (mod)	0	3 (25%)	1 (13%)
IV (sev)	3 (30%)	0	1 (13%)
V (sev)	7 (70%)	9 (75%)	6 (75%)
WAZ(British 1990)	-4.77 *SD 1.87*	-4.84 *SD 1.85*	-4.37 *SD 1.82*
WAZ(CP 2006) (>2 yrs only)	-3.10 (*n*=8) *SD 1.10*	-2.86 (*n*=10) *SD 1.93*	-2.18 (*n*=6) *SD 1.75*
Chest infections – at least once every 3 months	70%	83%	75%

The results in displayed in table 3-1 illustrate the homogeneity of the participants in all groups. The average age of the children was less than 5 years. The mean age of the youngest 70% was under 3 years in both cohorts, however the age range within C1 was greater, comprising three children >5years of age, as opposed to just one in the C2 cohort. The gender mix was similar in C1 and C2, however, the C2 drop-out group contained a higher proportion of males. The type and severity of CP was similar across the groups with the majority (>70%) rated at the most severely affected end of the scale (level V) on the Gross Motor Classification System (GMFCS; Palisano, 1997). The remainder in C1 (*n*=3) were rated at level IV, whereas C2 contained four children rated at level III (one of whom dropped out before training). The mean WAZ of the children was similar at first assessment, ranging between -4.37 and -4.84 WAZ (British 1990 Growth Reference Standards; Cole *et al*., 1998).

Differences between the children in the groups may be accounted for by differences in severity of the child's feeding impairment, the feeding skills of the caregiver, the child's general health, their age (anthropometric values in older children are further from the

norm (Stevenson *et al.*, 1994), and varying food security between slums (Helen Keller International, 2002).

3.1.3 The caregivers and households at baseline

This section includes baseline information on the carers' biodata, socioeconomic status, previous contact with services, psychological well-being, priority given to the child's feeding difficulties and their account of the mealtime experience. It also uses these data to make a baseline comparison of the carers in the two cohorts, including those C2 carers who dropped out after the post-advice review (PAR).

3.1.3.1 **Biodata** (FORM 1)

In the majority of cases, the main caregiver was the mother. With the exception of two, one of whom was an aunt (of only 10 years of age) and the other a grandmother. In two instances childcare was shared, one with the father and the other with the grandmother. (Both co-carers came to the training). The majority of the caregivers were aged between 16 and 25 years.

3.1.3.2 **Social & educational** (FORM 1 and Poverty Mapping Scale)

86% of families belonged to the poorest category on the Poverty Mapping Scale (Bhuiya *et al.*, 2007) and, where known, reported a mean monthly household income of 5124.71 Bangladeshi Taka (Tk). This is equivalent to approximately 74.51 US Dollars (calculated on 30.01.09). Food availability (with regards to feeding the disabled child) was reported to be an issue by 20% of carers.

The families were small, with fewer than two children on average. The majority of participants lived in nuclear as opposed to joint families (22 versus 14 respectively) and of the latter, 43% were with the mother's family.

19% of caregivers had received no schooling, 56% had completed primary education and 8% had continued schooling beyond primary. In terms of additional domestic demands only six caregivers were caring for a child younger than the one enrolled in the programme. (13 families had older siblings). Only two mothers were separated from their husband and one was a widow, however only 35% said they felt supported by their husband and family and local community, with 43% saying that their husband's family in particular was unsympathetic to their situation with regards to having a disabled child.

3.1.3.3 **Contact with services** (FORM 3)

35% of the carers reported to have had no previous contact with a disability service, or contact on one occasion only.

3.1.3.4 **Psychological well-being** (SRQ20)

In terms of psychological well-being, 31 scores were obtained at baseline on the Self-Reporting Questionnaire 20 items (SRQ20; Harding *et al*., 1980). A cut-off point for 'psychiatric morbidity' of >7 is given by Mari and Williams (1985). The mean score in our sample was 10.39 (*SD* 4.4), with 74.2% scoring above 7, illustrating a high level of anxiety amongst the carers.

3.1.3.5 **Priority given to feeding problems** (FORM 3)

Although 19 out of the 22 C1 and C2 caregivers reported feeling *very* stressed about their child's feeding problems, only 7 (5 from C1; 2 from C2) identified feeding as one of their top three priorities. The other priorities given were usually sitting independently, walking and talking.

3.1.3.6 **The 'feeding experience'** (FORM 3)

When first interviewed, 89% of the caregivers reported feeling *very* stressed about their child's feeding problems. 90% of carers said that mealtimes took a long time. 76% reported mealtimes taking 30-60 minutes. Although initial researcher observations suggest mealtimes were considerably shorter than carers perceived them to be, 76% of carers reported spending between 2.5 and 5 hours per day feeding their child. 67% initially said they were sometimes short of time for feeding. Some were concerned that they frequently had to leave their child hungry.

When asked what bothered them most, the first issue raised was often the fact that their child did not eat like other children. The following major concerns were related to nutrition; the fact that the child could only eat a limited diet and was therefore severely undernourished, and that the child could not feed itself and so may go hungry (because the caregiver was busy).

> *"I always worry about my child because she's losing weight. If she had died when she was born that would have been better but now I don't know how I'm going to keep her alive".* (OPD03, BSL)

Comments relating to the difficulties and burden of care included the fact that feeding the child and preparing special food were time-consuming, carers felt tired and worn down because it was always they who had to feed their child, and were worried about the future.

"I can accept that he can't walk, but it annoys me that he doesn't eat, because it takes so much of my time." (CHC0402, PAR)

"Now she's only little but when she grows up it will be a real problem. Now I can feed her, but in the future it will be difficult physically for both me and my child." (MUP20, PAR)

"It's OK while I'm alive but when I die who will feed my chid? If she could sit by herself maybe someone else could feed her or it would be OK if she could feed herself." (MUP03, BSL)

Other comments included the fact that the child did not cooperate, feeling upset by their lack of communication skills and responsiveness and feeling sad for the child. Caregivers alluded to a sense of being unskilled and not knowing the right way to feed their child.

When asked how they felt during feeding, caregivers most often said they felt annoyed or angry because feeding took a long time, anger or despair because the child did not want to eat (even though it was hungry) and tired because it was an effort. Five caregivers said they felt annoyed when the child vomited because they had spent so long preparing the food and feeding it to them. Five said that feeding was so intolerable and at that moment, that it made them wish their child would die. Five admitted to hitting their child during feeding and three, to feeding the child less because they felt so angry. Only four caregivers said they could accept the situation.

"I feel angry sometimes and hit him when I have to force him hard to eat. At that time I have to hold all his limbs down in lying position." (MUP22, BSL)

"I beat her because it's hard work for me and it takes a long time." (CHC0502, PAR)

"I always feel impatient because he cries a lot, so I shout at him and bite him" (MUP23, PAR)

"When he cries it's deafening. I feel angry because the food spills out, he vomits and cries, and because he can't feed himself." (MUP23, PAR)

Additional comments included feeling afraid and guilty.

There was a strong sense that caregivers blamed their child for their abnormal feeding behaviours (ie. oral spillage, coughing, vomiting). When the child's tongue pushed food out of the mouth because its oral skills were inadequate for the consistency or amount given, caregivers understood this as the child rejecting the food. As Black (1999) states, this is an example of misinterpretation on the part of the caregiver due to lack of knowledge.

The highest priorities of feeding intervention for the caregivers at BSL were to reduce the negative features of feeding (92%), for their children to be able to eat more 'normal' food (65%), and for the child to be able to feed him/herself (46%). Other hopes were that the child could learn to sit for feeding, drink more and communicate better with regards to eating. Some caregivers said their priority was to learn to feed their child better.

3.1.3.7 Comparison of the caregivers

Key features of the caregivers whose outcomes are reported on in this chapter are illustrated in the table below.

Table 3-2 Comparison of caregivers and households at baseline

		C1 (N=10)	**C2 training** (N=12)	**C2 drop-out** (N=8)
Age of caregiver (yrs)	**0-16**	1 (10%)	0	0
	16-25	7 (70%)	8 (67%)	6 (*63%)*
	26-35	2 (20%)	2 (17%)	3 (*38%)*
	36-45	0	2 (17%)	0
Poverty mapping score	**45+ (poor)**	7 (70%)	12 (100%)	7 (*88%)*
	42-44 (low mid)	1 (10%)	0	1 (*13%)*
	39-41 (mid)	2 (20%)	0	0
	36-38 (upper mid)	0	0	0
	<35 (upper)	0	0	0
Income (Bangladesh Taka, BDT)		50% <5000 BDT	70% <5000 BDT (*n*=10)	86% <5000 BDT (*n*=7)
Food availability an issue		0	4 (25%)	2 (33%)
CG education	**No schooling**	1 (10%)	2 (17%)	1 (*13%)*
	Prim incomplete	3 (30%)	10 (83%)	2 (25%)
	Prim complete	5 (50%)	0	5 (*63%)*
	HSC complete	1 (10%)	0	0
Mean no. of siblings (living at home)		0.9 (*SD* 0.88)	0.3 (*SD* 0.65)	0.8 (*SD* 0.71)
Support at home	**0**	0	0	1 (*13%)*
	1	3 (30%)	1 (8%)	1 (*13%)*
	2	2 (20%)	2 (17%)	2 (25%)
	3	2 (20%)	3 (25%)	2 (25%)
	4	3 (30%)	6 (50%)	2 (25%)
SRQ20 scores		9.4 (*SD* 3.54) (*n*=9)	10.4 (*SD* 5.23)	12.1 (*SD* 4.16)
CG overall stress re fdg	**Not**	0	0	0
	A little	0	0	0
	Somewhat	2 (20%)	2 (17%)	0
	Very	8 (80%)	10 (83%)	8 (100%)
Feeding one of top 3 priorities for change		5 (50%)	2 (17%)	5 (63%)

Comparing all the caregivers and household there were few differences overall, with small differences in wealth and education, family size, mental well-being and level of support. The majority of the carers were the child's mother and were aged between 16 and 25 years.

Comparing C1 and C2 caregivers who received advice plus training, C1 included a greater range of income groups and educational histories. 100% of C2 caregivers belonged to the poorest category on the Poverty Mapping Scale (Bhuiya, 2004) whereas three of the C1 caregivers were in the lower middle or middle income groups. C1 families were overall slightly wealthier. None of the participants belonged to the highest two categories (upper-middle or upper). Food availability was an issue for 25% of C2 (training) children but not for the C1 children at the beginning of the programme. (This became an equal issue for both later). C2 caregivers had received less schooling with none having completed primary school. Five C1 caregivers had completed primary school and one continued to complete five years of secondary.

In terms of family size, six of the C1 households had more than one child, as opposed to only three families in the C2 (training) cohort. Most caregivers (80% and 83%) reported feeling *very* stressed about their child's feeding problems and scores on the SRQ20 tool were similarly high, however C2 (training) caregivers felt better supported than those in C1 with 50% and 30% respectively feeling well-supported by their families and community.

Caregivers who dropped out before the training programme were consistently stressed to the maximum level with regards to feeding, their SRQ20 scores were the highest of the three groups, they were the least wealthy of the participants and the average number of children living at home was more than double that of the C2 participants who continued. Perceived usefulness of the training was also lower amongst this group.

3.1.4 Pre-training feeding practices

3.1.4.1 **Food given** (FORM 3)

Children were fed on average five times a day, in contrast with the rest of the family who would eat three meals a day. When asked if their disabled child ate the same number of times per day as their non-disabled siblings when they were the same age, caregivers said that they ate less. The reason given was because they could not forage for food themselves thereby not being able to snack between meals.

Table 3-3 Frequency of food types eaten per day: child and family

	Child	Family
Milk-based	3.0	0.1
Fruit	1.0	0.7
Vegetables	1.2	2.6
Protein	1.7	3.2

The majority foods eaten by the disabled child were milk and carbohydrate-based foods given as a thick liquid or puree, and therefore low in nutritional content and calorie-density. This food is easier to give to children who cannot chew and is less costly and quicker to prepare than more nutritious soft foods such as khichuri, a nutritious rice-based weaning food used in Bangladesh. 41% of the food given was of a mixed consistency which increases the risk of aspiration during feeding.

On average, the children ate fruit and vegetables once a day and protein once or twice a day. In contrast, the family diet consisted of fruits being eaten once or less per day, vegetables two to three times, and protein approximately three times. The main family foods were a more balanced mixture of carbohydrate, protein and vegetables. The differences are summarised in the table above.

Food was given using an array of utensils including dessert spoons, feeder bottles and in one case, a Chinese soup spoon. These utensils add to the risk of aspiration because they require the child to eat larger mouthfuls and more quickly than they can manage effectively and safely.

The children were given on average less than 200 millilitres (ml) of drinks per day with approximately 30% of children reportedly receiving less than 75mls per day. Such small quantities suggest that the children in this study would be would have been severely dehydrated. Drinking was an area caregivers highlighted as particularly problematic.

3.1.4.2 **Positioning** (FORM 7)

At the first mealtime observation, children were mainly fed in lying or breastfeeding position rather than semi-reclined or upright. Head positioning was observed in extension (very or slightly extended) in 100% of cases at some point during the assessment. The table below illustrates the number children who were observed in these positions at any point in the initial assessment.

Table 3-4 Feeding positions at baseline: percentage of children observed in each position at any time

	Lying	Breastfeeding	Semi-reclined	Semi-reclined to upright
FOOD	32.4	40.5	21.6	16.2
DRINK	27.3	54.5	18.8	18.8

3.1.4.3 Caregiver interaction style and responsiveness (FORMS 3 and 7)

At first observation, caregiver interaction styles during feeding were predominantly negative. Positive verbal encouragement was observed *never* or *occasionally* in 84% of initial mealtime observations. Negative verbal interactions were reported or observed in 80% of cases and negative physical behaviour reported or observed in 87%. Researcher observations showed 89% of children to be fed either too fast, given too much food in each mouthful or both. 49% of children were reported not to be fed when they were hungry but rather when their caregivers had time.

3.1.4.4 Training needs (FORM 8)

The most commonly identified aims of training (identified by the researcher in 80% or more of the child-caregiver pairs) and specific training needs are summarised in table 3-5 and 3-6 below.

Table 3-5 Most frequently identified aims of training

Child	Caregiver
▪ Reducing risks of aspiration ▪ Increasing fluid intake ▪ Improving nutritional status	▪ Increasing positive proactiveness ▪ Increasing responsiveness of feeding manner

Table 3-6 Most frequently identified training needs

▪ Improve positioning	100%
▪ Increase drinks	94%
▪ Provide verbal encouragement	92%
▪ Improve manner of delivery	89%
▪ Change utensil (food or drink)	82%
▪ Improve diet	81%
▪ Change food consistency	78%

The least identified training targets were the implementation of oral desensitisation / oromotor exercises, sensory preparation for feeding, the management of oral spillage with drinks and the modification of drink consistency. The reason for areas being least targeted was largely pragmatic; balancing what was realistic to expect caregivers to change and what behaviour changes would have the most significant impact. Verbal and sensory preparation became subsumed in the target for positive proactiveness (unless the child had specific needs related to sensory impairments) and support for

self-feeding drinks was rarely an appropriate goal due to the children's level of motor ability.

Although the literature suggests there should be a correlation between caregiver mental well-being and responsiveness and sensitivity of feeding manner (Hurley *et al.*, 2008), none was found in this study. Using a Pearson Product Moment Test of correlation to analyse the data available (n=36) an association was found however, between caregiver level of education and the number of training targets initially identified, with lower levels of education being correlated with higher numbers of training needs ($R(34)=0.40$, $p<0.05$).

3.2 Impact of the intervention on the children

The impact of the intervention on the child was assessed in the areas of nutritional status, chest health, discomfort or distress experienced during feeding and feeding skills. Additional perceived outcomes are reported from caregiver comments.

3.2.1 Nutritional status and fluid intake

3.2.1.1 Nutritional status

As outlined in the Methods chapter, nutritional status was assessed through anthropometric measurement and changes were assessed through changes in weight-for-age *z*-scores (WAZ) and mid-upper arm circumference *z*-scores (MUACZ). It was not possible to calculate weight-for-height using the chosen growth references. Measures relating to ponderal growth were chosen in this study as these more accurately reflect changes associated with energy intake. In order to calculate *z*-scores, the British 1990 growth reference standards were used ((British 1990)), adopting the LMS method (Cole *et al*., 1998). These were used rather than the WHO standards (2006) as with the former, it was possible to include all of the data (WHO has a cut-off of 10 years). (A comparison of the changes in *z*-scores calculated for children under 10 years using both methods showed little difference between them). MUAC scores could not be converted to *z*-scores using this programme, however it is common practice to report them as raw values as MUAC is known to vary little according to age. The nutritional outcomes were also assessed using the CP growth charts (Stevenson *et al*., 2006), which can only be used for children over 2 years of age.

Interpretation of the data includes statistical analysis as well as a judgement of clinical significance based on the work by Ong *et al. (*2000). In their research, they suggest a change of 0.67 *z*-sores in children aged 0-2 years as clinically significant (positively or negatively). In the current study, a value of 0.5 *z*-scores has been chosen, taking into account the slower growth rate of the CP population, (Stevenson *et al*., 1994; Samson-Fang and Stevenson, 1998).

The tables below summarise the changes in mean WAZ and MUAC over time. It was possible to include 11 children from the C1 cohort in the analysis (as opposed to the usual 10), as all of the anthropometric data had been collected on one child for whom interview data was incomplete. Row one in the tables includes all of the children in the cohorts, row two provides the results of those above 2 years of age using the British 1990 growth standards to compare them with row three, which illustrates the children over 2 years using the CP growth charts.

Table 3-7 Mean weight-for-age *z*-scores

C1&C2		BSL	PTR1	PTR2
British 1990 growth reference standards (Cole *et al*., 1998)	*n=23*	**-4.83**	**-4.90**	**-4.07**
	SD	*1.84*	*2.10*	*2.45*
British 1990 growth reference standards (Cole *et al*., 1998) >2 years	*n*=18	**--5.33**	**-5.25**	**-4.52**
	SD	*1.53*	*1.86*	*2.47*
CP growth charts (Stevenson *et al*., 2006)	*n*=18	**-2.97**	**-2.52**	**-2.32**
	SD	*1.90*	*2.07*	*1.59*

C2A		BSL	PAR
British 1990 growth reference standards (Cole *et al*., 1998)	*n=20*	**-4.65**	**-4.32**
	SD	*1.80*	*1.85*
British 1990 growth reference standards (Cole *et al*., 1998) >2 years	*n=16*	**-4.53**	**-4.32**
	SD	*1.75*	*1.85*
CP growth charts (Stevenson *et al*., 2006)	*n =16*	**-2.61**	**-2.38**
	SD	*2.03*	*1.63*

Table 3-8 Mean MUAC/MUACZ

C1&C2		BSL	PTR1	PTR2
British 1990 growth reference standards (Cole *et al*., 1998). Raw score (cm)	*n*=23	**14.75**	**15.04**	**15.46**
	SD	*1.41*	*1.81*	*1.57*
British 1990 growth reference standards (Cole *et al*., 1998). Raw score (cm)	*n*=18	**14.92**	**15.17**	**15.43**
	SD	*1.34*	*1.81*	*1.75*
CP growth charts (Stevenson *et al*., 2006). *z*-score	*n*=18	**-0.42**	**-0.44**	**-0.37**
	SD	*0.58*	*0.83*	*0.68*

C2A		BSL	PAR
British 1990 growth reference standards (Cole *et al*., 1998). Raw score (cm)	*n*=20	**14.84**	**15.12**
	SD	*1.49*	*1.55*
British 1990 growth reference standards (Cole *et al*., 1998). Raw score (cm)	*n*=16	**14.72**	**15.02**
	SD	*1.35*	*1.54*
CP growth charts (Stevenson *et al*., 2006). Z-score.	*n*=16	**-0.50**	**0.43**
	SD	*0.67*	*0.71*

The following tables summarise the changes in *z*-score between baseline and PTR2 (C1 & C2) and baseline and PAR (C2A), for WAZ and MUACZ.

Table 3-9 Summary of changes of >0.5 *z*-scores

C1&C2 (BSL to PTR2)	+0.5 *z-scores*	-0.5 *z-scores*
WAZ (British 1990, *n*=23)	6	6
WAZ (CP 2006, *n*=18)	4	1
MUACZ (CP 2006 , *n*=18)	2	2

C2A (BSL to PAR)	+0.5 *z-scores*	-0.5 *z-scores*
WAZ (British 1990, *n*=20)	7	0
WAZ (CP 2006, *n*=16)	2	0
MUACZ (CP 2006, *n*=16)	0	0

Advice plus training

WAZ: A calculation of weight change by applying the British 1990 reference standards (Cole *et al*., 1998) and using a one factor within-subjects analysis of variance (ANOVA), showed a statistically significant increase in weight *z-score*s overall. This was greater when including values for all of the C1 and C2 children ($F(2,42)=4.88$, $p=0.01$) compared with the outcomes for those over 2 years of age only ($F(1,17)=4.52$, $p<0.05$). When the outcomes for PTR1 and PTR2 were analysed separately, little or no improvement was observed at PTR1, however a Paired Samples *t*-test showed a significant increase in both groups by PTR2 ($t(22)=2.46$, $p<0.05$; $t(17)=-2.13$, $p<0.05$).
In terms of clinical change, 6 of the 23 children analysed gained by >0.5 *z*-scores in weight and 6 lost. The other changes were all within 0.5 *z-score*s. Overall, 13 children (59%) improved or maintained their growth trajectories.

Analysis when applying the CP growth charts (Stevenson *et al*., 2006), showed a mean increase of 0.65 WAZ, which was not statistically significant ($p=0.17$). However, using these charts, the number of clinically significant increases verses decreases was 4 versus 1.

The outcomes for WAZ are illustrated in figures 3.2 and 3.3 below.

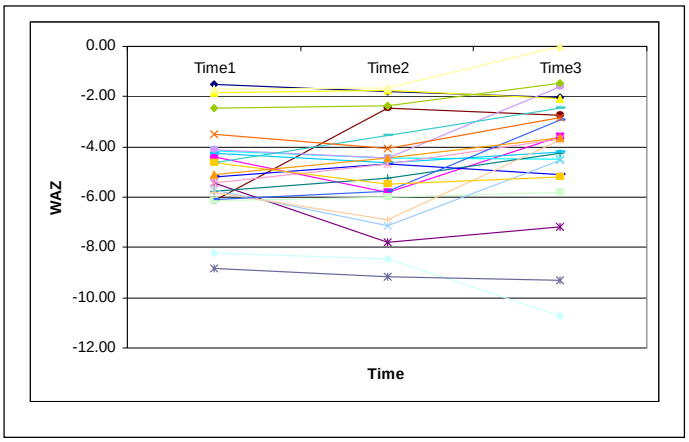


Figure 3.2 WAZ outcomes: British 1990 growth references (*n*=23)

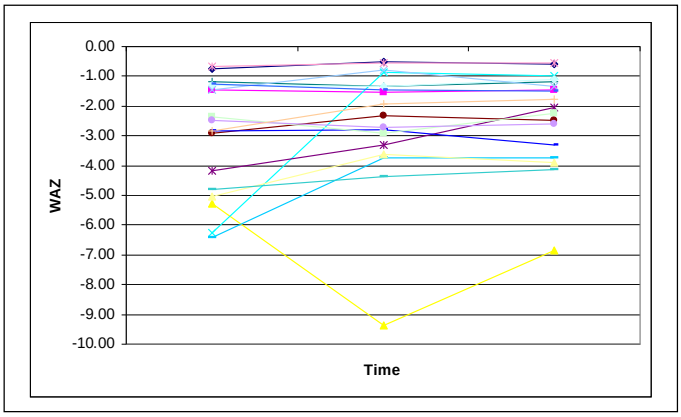


Figure 3.3 WAZ outcomes: CP growth charts (*n*=18)

MUAC/MUACZ: Analysis of the raw MUAC scores showed a significant overall increase using all of the values ($F(2,44)=8.20$, $p=0.001$) and when analysing values from the children over 2 years only ($F(1,17)=6.52$, $p<0.05$). Significance was achieved in both data sets at PTR2 ($t(22)=3.614$, $p<0.005$; $t(17)=2.55$, $p<0.05$) though not at PTR1 ($t(22)=1.822$, $p=0.08$; $t(17)=1.261$, $p=0.23$). Analysis of the MUAC z-scores, applying the CP growth charts (Stevenson *et al*., 2006), were slight and not significant ($p=0.78$) however. Using these reference standards, 2 children showed an increase of >0.5 *z*-scores and 2, a decrease of the same amount. (The other changes remained within 0.5 *z*-scores).

Advice only

WAZ: Applying the British 1990 reference standards (Cole *et al*., 1998) and using a Paired Samples *t*-test, no overall change was observed in the WAZ either when analysing the whole data set ($t(19)=0.70$, $p=0.49$) or data from those who were over 2

years of age (t(15)=1.18, p=0.26). However, 7 children gained by >0.5 z-scores in WAZ and none lost by the same amount. Applying the CP growth charts, the change in WAZ was small, and again, not significant (t(15)=1.12, p=0.28).

MUAC/MUACZ: The increase in raw MUAC scores was significant for both data sets (t(19)=4.18, p=0.001; t(15)=3.43, p<0.01). Changes in MUACZ$_{(CP\ 2006)}$ (>2 years of age) were not statistically significant (t(15)=1.80, p=0.09), and no children made increases or decreases in MUACZ of >0.5 z-scores.

Summary of anthropometric outcomes

Following *advice plus training*, the mean weight-for-age z-scores, when applying the British 1990 growth references, increased significantly for the whole data set, as well as for those over 2 years of age only. When applying the CP growth charts, the change for those over 2 years of age was not statistically significant. Raw scores for MUAC increased significantly, however MUACZ$_{(CP\ 2006)}$ scores for those over 2 years of age did not.

In terms of clinical change (ie change greater than 0.5 z-scores), 6 of the C1 and C2 children increased and 6 decreased in WAZ using the British 1990 growth references, however the number of gains and losses was 4 and 1 respectively, using the CP growth charts. MUACZ$_{(CP\ 2006)}$ in those over 2 years of age increased by >0.5 z-scores in 2 cases and decreased in 2.

Following *advice only*, neither changes in WAZ (using the British 1990 and CP growth charts) nor changes in MUACZ$_{(CP\ 2006)}$ (>2years) were statistically significant. Increases in MUAC raw scores were significant however.

In this group, clinically significant increases in WAZ, using the British 1990 growth references, were observed in 7 children and decreases in none. Using the CP charts however, clinical increases were observed in 6 and losses in 6. There were no gains or losses in MUACZ$_{(CP\ 2006)}$ (>2years) of >0.5 z-scores.

Overall, when comparing children within the same age group, greater statistical significance was achieved in the analysis of the results when using the British 1990 rather than the CP growth standards. However, less variation between the values for the children was observed when using the latter.

Using the British 1990 references, the degree of statistical significance was higher when analysis included the children below 2 years of age.

It should be noted that the C2 children made significantly greater improvements than the C1 children in $WAZ_{(British\ 1990)}$ scores ($t(20)=2.82$, $p=0.01$).

These results are discussed in Chapter 4.

3.2.1.2 Hydration

Hydration was not assessed, however it was possible to estimate the amount of liquid consumed through drinks, the details of which are reported later in this chapter (see Training Outcomes, section 3.4.2.2). Improvements were reported in fluid intake through drinks, however, the levels remained severely inadequate (see recommended daily amounts above). Both the C1 and C2 children were still consuming less than 300ml of drinks daily after training.

3.2.2 Chest health

Chest health was assessed through risk of aspiration during feeding and frequency of chest-related illnesses.

3.2.2.1 Risk of aspiration during feeding

(i) Observation of pharyngeal signs during feeding (FORM 7)

During the mealtime observations, signs of feeding difficulty at the pharyngeal level were identified as occurring *occasionally* (ie. 1-3 times or <10% of the mealtime) or *frequently* (ie. periodically or consistently throughout the meal). The mean values for signs observed frequently (food and drink combined) are shown in table 3-10. (Non-parametric tests were used as the data were not normally distributed).

Table 3-10 Mean number of frequently observed pharyngeal signs

Advice plus training		BSL	PTR1	PTR2
C1 & C2	Mean	2.3	0.9	0.7
	SD	*3.11*	*1.12*	*1.42*

Advice only		BSL	PAR
C2A	Mean	1.4	1.5
	SD	*2.48*	*1.93*

Advice plus training

The mean number of pharyngeal signs observed on a frequent basis reduced by 70% between BSL and PTR2. Using a Friedman Test, this change was found to be significant overall (Chi-Square=8.29, df=2, p<0.05) and, using a Wilcoxon Signed Ranks Test, this was significant at each review (PTR1: Z=2.01, p<0.05; PTR2: Z=2.22, p<0.05).

Advice only

There was no reduction in pharyngeal signs seen after advice only (Z=0.20; p=0.87).

(ii) Reported frequency of coughing during feeding (FORMS 3, 9, 10 , 11)

The scores below are from caregiver reports on the frequency of children's coughing on food and drink. Points were allocated as follows: *Always* (2); *sometimes* (1); *never* (0). Scores for food and drink were combined giving a maximum score of 4.

Table 3-11 Mean score of reported coughing (Maximum potential score of 4)

	BSL	PTR1	PTR2
C1&C2	2.5	1.5	1.0
SD	*1.14*	*1.26*	*1.16*

	BSL	PAR
C2A	2.3	1.9
SD	*0.80*	*0.75*

Advice plus training

Using a Friedman Test, a significant overall reduction was found in reported coughing (Chi-Square=21.581, *df*=2, *p*<0.001). A Wilcoxon Signed Ranks Test showed this change to be significant at PTR1 (*Z*=3.13, *p*<0.005) and at PTR2 (*Z*=3.60, *p*<0.001).

Advice only

Reports of coughing also reduced significantly following *advice only* (*Z*=2.07, *p*<0.05).

(iii) Reported frequency of chest-related illness (FORMS 3, 9, 10 , 11)

Data taken from caregiver reports of chest-related illness ('cold with fever', 'chesty cold') between visits were averaged out and converted to a percentage of the number of cases reported in one of four time categories (less than 3 monthly (1), every 2-3 months (2), monthly (3), more than once a month (4))

The data were also converted to a mean score of frequency of sickness, converting the time categories into scores (1-4). The results are illustrated in the table below.

Table 3-12 Mean score of frequency of chest-related illness

	BSL	PTR1	PTR2
C1&C2	**1.2**	**0.7**	**0.5**
SD	*1.01*	*0.95*	*0.74*

	BSL	PAR
C2A	**1.3**	**0.8**
SD	*1.12*	*1.07*

Advice plus training

Using a Friedman Test, reduction in the frequency of chest-related illnesses was found to be overall significant (Chi-Square=13.38, *df*=2; *p*=0.001). A Wilcoxon Signed Ranks Test showed change to be achieved at PTR1 (*Z*=2.50, *p*=0.01, ties 12[7]) and sustained to PTR2 (*Z*=2.96, *p*<0.005). 35% of C1 and C2 children were experiencing chest-related illnesses once or more per month at BSL. This reduced to 15% and 14% at PTR1 and PTR2 respectively.

Advice only

Significant change was also observed following advice only (*Z*=2.06, *p*<0.05, ties13). Chest-related illnesses occurring once or more per month reduced from 45% at BSL to 25% at PAR.

[7] The number of ties incurred is reported where this is greater than the total number of positive and negative ranks, in order to aid interpretation of the results.

3.2.3 Child affect

Levels of discomfort and distress experienced during feeding were assessed through researcher observations and caregiver reports of child crying, fussiness, food refusal and general affect at mealtimes.

3.2.3.1 Observed level of discomfort/distress during feeding (FORM 7)

A child was considered to be uncomfortable if they showed signs if irritability and mild complaining through facial expression, body movements and vocalisations. A child was considered to be distressed if they were crying or screaming.

The levels of discomfort/distress observed in the children were converted to a mean score using the 6-point rating scale employed in the observations: *Discomfort occasionally* (1); *discomfort sometimes* (2); *discomfort mostly* (3); *distress occasionally* (4); *distress sometimes* (5); *distress mostly* (6).

Table 3-13 Mean score of observed discomfort/distress

	BSL	PTR1	PTR2
C1&C2	**1.9**	**0.4**	**0.8**
SD	*2.17*	*0.73*	*1.22*

	BSL	PAR
C2A	**1.7**	**1.5**
SD	*2.11*	*1.67*

Advice plus training

Using a Friedman Test, changes in discomfort and distress were found to be significant overall (Chi-Square=10.36, *df*=2, *p*<0.01). A Wilcoxon Signed Ranks Test showed significance to be achieved at PTR1 (*Z*=2.62, *p*<0.01) but the change was not quite significant at PTR2 (*Z*=1.89 *p*=0.06). In fact, the number of children observed to be in discomfort *some* or *most of the time*, reduced from 18% at BSL to 0% at PTR1, then rose again to 17% at PTR2. The number of those who displayed signs of distress *some* or *most of the time* reduced from 19% at BSL to 0% at PTR1 and PTR2. (Increases in signs of discomfort may be related to decreases in signs of distress, as they are scored on one continuum).

Advice only

Using the mean scores, the results did not change overall (*Z*=0.32, *p*=0.75). Although the percentage of C2A children observed to be experiencing discomfort *some* or *most of the time* increased from 15% at BSL to 25% at PAR, the number showing signs of distress decreased from 15% to 5% at PAR.

3.2.3.2 Caregiver reports of crying during feeding (FORMS 3, 9, 10, 11)

Caregiver reports on the frequency of their children's crying during feeding were converted into scores. Points were allocated as follows: *Always* (2); *Sometimes* (1); *Never* (0). The mean scores are displayed in the table below.

Table 3-14 Mean score of crying (Maximum potential score of 3)

	BSL	PTR1	PTR2
C1&C2	**1.0**	**0.4**	**0.3**
SD	*0.84*	*0.58*	*0.46*

	BSL	PAR
C2A	**1.1**	**0.6**
SD	*0.76*	*0.60*

Advice plus training

Using a Friedman Test, an overall significant reduction was observed in the reported frequency of child crying during feeding (Chi-Square=11.54, *df*=2, *p*<0.005). A Wilcoxon Signed Ranks Test showed change to be significant at PTR1 (*Z*=2.50, *p*<0.05) and PTR2 (*Z*=2.88, *p*<0.005, ties 12). The number of children who *always* cried during feeding was reduced from 33% to 5% at PTR1 and 0% at PTR2. The number who reportedly *never* cried doubled (from 36% at BSL to 73% at PTR2).

Advice only

There was also a significant decrease in reported crying following advice only (*Z*=2.18, *p*<0.05). There was a decrease, from 30% to 5%, of children reported to *always* cry during feeding and an increase, from 25% to 45%, of those reported to *never* cry.

3.2.3.3 Reported fussiness / particular re food (FORMS 3, 9, 10 , 11)

Caregivers were asked if their children were 'fussy-eaters' (yes or no). The results are shown in the table below.

Table 3-15 Percentage of children reported to be fussy eaters

	BSL	PTR1	PTR2
C1&C2	64	33	27

	BSL	PAR
C2A	70	65

Advice plus training

There was a decrease of >50% in the frequency of fussiness reported by carers following advice plus training, which, using a Freidman Test was found to be significant overall (Chi-Square=12.67, *df*=2, *p*<0.005). A Wilcoxon Signed Ranks Test showed change to be significant at PTR1 (*Z*=2.65, *p*<0.01, ties 15) and PTR2 (*Z*=2.83, *p*=0.005, ties 14).

Advice only

There was little change following advice only, which was not significant (*Z*=3.78, *p*=0.71, ties 13).

3.2.3.4 Reported food refusal (FORMS 3, 9, 10 , 11)

Caregivers reports on the frequency of food refusal were converted into scores, as follows: *Always* (2); *sometimes* (1); *never* (0) and the results are summarised in the table below.

Table 3-16 Mean score of food refusal (Maximum potential score of 3)

	BSL	PTR1	PTR2
C1&C2	**1.4**	**0.7**	**0.8**
SD	*0.58*	*0.57*	*0.53*

	BSL	PAR
C2A	**1.2**	**1.2**
SD	*0.52*	*0.59*

Advice plus training

Using mean scores, the overall food refusal reduced by almost 50% which, using a Freidman Test was found to be overall significant (Chi-Square=15.06, *df*=2, *p*=0.001). A Wilcoxon Signed Ranks Test showed change to be significant at PTR1 (*Z*=3.10, *p*<0.005) and PTR2 (*Z*=2.97; *p*<0.005). At baseline, food refusal was reported in 96% of C1 and C2 children, *always* or *some of the time*. This reduced to 73% at PTR2. The number of those who reportedly *always* refused food decreased from 41% to 4%.

Advice only

There was no change following advice only.

3.2.3.5 Reported changes in child affect during feeding (FORMS 3, 9, 10 , 11)

When asked "What changes have you observed in your child since enrolling in the programme?" caregivers increasingly commented that they were happier, less distressed and cooperating more at mealtimes. This was commented on by 50% of the carers at PAR, and almost all of the carers at PTR1 and PTR2.

My child laughs now. Before, she cried a lot. Now when I feed my child she responds well. She finds eating is easier. Before, she used to get annoyed. (MUP10, PTR1)

"He was screaming before with all food and I had to force him, but now he eats without screaming and I don't have to force him." (CDC03, PAR)

3.2.4 Child feeding skills

The feeding skills examined were oral skills and involvement in self-feeding. Oral skills were measured by identifying the child's developmental stage of feeding and degree of oral spillage. These were assessed using researcher observations and caregiver reports. Self-feeding was assessed through researcher observations alone.

3.2.4.1 **Observed change in maturity of oral feeding manner** (FORM 7)

During the mealtime observations, children's feeding patterns were observed and rated. The percentage of children observed at each stage of feeding is summarised in the table below. The stages of feeding most commonly observed are shaded, with the darkest shade representing the highest proportion.

Key: 1: Sucking
2: Sucking-to-munching transition
3: Munching
4: Munching-to-chewing transition
5: Chewing

Table 3-17 Percentage of children observed at different stages of feeding maturity

	BSL					PTR1					PTR2				
	1	**2**	**3**	**4**	**5**	**1**	**2**	**3**	**4**	**5**	**1**	**2**	**3**	**4**	**5**
C1&C2	23	50	24	0	4	0	33	38	21	8	0	18	47	19	16

	BSL					PAR				
	1	**2**	**3**	**4**	**5**	**1**	**2**	**3**	**4**	**5**
C2A	20	35	35	5	5	10	40	35	5	10

The stages of oral feeding observed in the children can be represented as a mean score using the 5-point scale of feeding maturity outlined in the key above, as illustrated in the table below.

Table 3-18 Mean score of maturity of oral feeding

	BSL	PTR1	PTR2
C1&C2	**2.1**	**3.1**	**3.4**
SD	*0.94*	*0.97*	*1.0*

	BSL	PAR
C2A	**2.4**	**2.9**
SD	*1.05*	*1.31*

Advice plus training

A gradual progression towards more mature feeding patterns was observed. Using a Friedman Test, these changes were found to be significant overall (Chi-Square=22.22, p<0.001). A Wilcoxon Signed Ranks Test showed these to be significant at PTR1 (Z=2.99, p<0.005) and PTR2 (Z=3.34, p=0.001).

Advice only

Although some progress was observed in this group, it was not quite significant (*Z*=1.769, *p*=0.08, ties 15).

It should also be noted that progress to chewing itself would not be expected for the majority of the children due to the severity of their cerebral palsy.

3.2.4.2 Researcher observations of oral spillage (FORM 7)

The number of children displaying consistent and marked oral spillage was recorded using the mealtime observations, as shown in the table below.

Table 3-19 Percentage of children displaying marked oral spillage during feeding

	BSL	PTR1	PTR2
C1&C2	92	70	67

	BSL	PAR
C2A	75	55

Advice plus training

Using a Cochran Test, reductions in levels of oral spillage were shown to be overall significant (*Q*=6.25, *p*<0.05). When analysed separately using a McNemar Test, the results for PTR1 and PTR2 were not quite significant however (PTR1: *p*=0.06; PTR2: *p*=0.06).

Advice only

Despite a fairly substantial drop following advice only, the reduction was not significant (p=0.13).

Observations showed that spillage had only reduced in 5 out of the 22 children (C1 and C2 combined) but because all 5 changed in a positive direction, the overall results were significant. Considering the fact that this was a very disabled group of children and that the measure used provided a binary result (Yes/No), therefore lacking the sensitivity to show greater change, the results are encouraging however.

3.2.4.3 Reported oral spillage (FORMS 3, 9, 10, 11)

Caregivers reports on the frequency of oral spillage were converted into scores, as follows: *Always* (2); *sometimes* (1); *never* (0) and the results are summarised in the table below.

Table 3-20 Mean score of reported oral spillage

	BSL	PTR1	PTR2
C1&C2	1.5	0.9	0.9
SD	*0.80*	*0.89*	*0.87*

	BSL	PAR
C2A	1.5	1.3
SD	*0.69*	*0.85*

Advice plus training

Using a Friedman Test, an overall significant reduction was observed in the frequency of reported oral spillage during eating (Chi-Square=8.26, *df*=2, $p<0.05$). A Wilcoxon Signed Ranks Test showed this change to be significant at PTR1 ($Z=2.02$, $p<0.05$) but not at PTR2 ($Z=1.70$, $p=0.09$). The number of children reported to *always* spill decreased from 67% to 33% at PTR2, and those reported to *never* spill increased from 19% to 41%.

Advice only

There was a small change in the mean score following *advice only*, which was not significant ($Z=1.10$, $p=0.27$, ties 12), however the number of children reported to *never* spill increased from 10% to 25% at PAR.

3.2.4.4 Reported improvements in oral feeding skills (FORMS 9, 10, 11)

Several caregiver responses to the question regarding observable changes in their child since enrolling in the programme pertained to improvements in oral feeding skills, including the fact that the child could eat more easily, was drinking better, was able to manage a greater range of food textures and that their swallowing had improved.

> *"He used to spill a lot of food from his mouth when eating. Now he spills food rarely."* (MUP17, PTR1)
>
> *"She struggles less with food and is beginning to chew a little."* (MUP08, PTR1)
>
> *"He can now chew and move his tongue. Now he can swallow food better."* (CHC0407, PTR2)
>
> *"He drinks water well. He used not to be able to drink water at all."* (CHC0408, PTR2)
>
> *"He can manage more normal food. He doesn't cough or vomit or get irritated. He's eating well."* (MUP19, PTR2)
>
> *"Before when I fed him he vomited and he had no strength. Now, even though he only eats a little, he has more strength."* (CDC01, PAR)

3.2.4.5 Observed involvement in self-feeding (TOOL 7)

During mealtime observations, children were rated as *never* (0), *occasionally* (1) or *mostly* (2) involved in self-feeding. A mean score was derived from these ratings and the results are displayed in the table below.

Table 3-21 Mean score of self-feeding (maximum potential score of 2)

	BSL	PTR1	PTR2
C1&C2	**0**	**0.3**	**0.4**
SD	*0.00*	*0.55*	*0.66*

	BSL	PAR
C2A	**0**	**0.4**
SD	*0.00*	*0.60*

Advice plus training

Using a Friedman Test, a statistically significant increase was observed in the number of children who became involved in self-feeding overall (Chi-Square=8.82, $p<0.01$). A Wilcoxon Signed Ranks Test showed this change to be significant at PTR1 ($Z=2.12$, $p<0.05$, ties 17) and PTR2 ($Z=2.27$, $p<0.05$, ties 17). 100% of the C1 and C2 children were totally uninvolved in self-feeding during the BSL mealtime assessments. At PTR2, this had increased to 19% being involved occasionally and 8% feeding themselves during most of the meal.

Advice only

Significant change was also achieved after advice only ($Z=2.53$, $p<0.01$, ties 13), with 30% of children observed to be involved in self-feeding occasionally and 5% feeding themselves during most of the meal at PAR.

In spite of the significant results, positive changes were observed in only 6 children (the least disabled) following advice plus training and seven following advice only. The results are significant for all the groups partly because of the low starting point (100% not involved in self-feeding) and because of the fact that no one could deteriorate. This means that a few positive changes gave statistically significant results. It should be noted that outcomes in self-feeding were higher in the C2 cohort due to the difference in levels of disability of the children.

The cultural barriers to allowing a child to self-feed coupled with observable child resistance and a high degree of child disability meant that any improvements in this area were nonetheless regarded as a great achievement.

3.2.5 Additional reported benefits to the child

3.2.5.1 Caregiver qualitative statements (FORMS 9, 10, 11)

Additional feeding-related benefits perceived by caregivers included improved communication skills at mealtimes, increased food intake and habituation to sitting for feeding.

3.2.5.2 General Health (FORMS 9, 10, 11)

Caregivers were asked to report on the health of their children between visits, to give an idea of the child's health patterns over a period of months. The data were averaged out to enable a score for frequency of illness per child. This information was not collected at baseline and so comparison of the data is only possibly between PAR and PTR1/PTR2 (ie. involving C2 children only (*n*=12)). Due to the small numbers, the analysis should therefore be interpreted with caution.

A mean score of sickness was derived from the results which were categorised into to sickness occurring *less than once a month* (0), *once a month* (1) or *more than once a month* (2), as shown in the table below.

Table 3-22 Mean score of sickness (C2)

	PAR	PTR1	PTR2
C2	**0.8**	**0.2**	**0.5**
SD	*0.62*	*0.39*	*0.80*

Although the mean scores of sickness fluctuated across time and did not reduce significantly between PAR and PTR2, there was, however, a 50% reduction in the number of C2 children who were reported sick once or more every month at PTR2, suggesting an overall improvement in the children's health.

Improvements in child health were also mentioned in response to the question at PTR2, 'What changes, if any, do you see in your child since enrolling in the programme' (FORM 10).

It should be noted that the fact that the C2 cohort underwent their second review further into the monsoon season may account for the reduction in health between PTR1 and PTR2.

3.2.5.3 General mood

(i) Caregiver reports (Quantitative) (FORMS 3, 9, 10, 11)

Caregivers were asked to rate the predominant mood of their children as generally negative (0), neither positive nor negative (1), or positive (2). Using these ratings, a mean rating of 'positivity' for the children was calculated, with a maximum score of 2 points, as follows.

Table 3-23 Mean rating of 'positivity'

	BSL	PTR1	PTR2
C1&C2	**0.6**	**1.8**	**1.8**
SD	*0.95*	*0.61*	*0.61*

	BSL	PAR
C2A	**1.1**	**1.6**
SD	*1.00*	*0.83*

Advice plus training

Using a Friedman Test, reported improvements in mood were found to be significant overall (Chi-Square=24.73, p<0.001) and using a Wilcoxon Signed Ranks Test, significance was shown at both PTR1 and PTR2 (PTR1: Z=3.5, p<0.001; PTR2: Z=3.5, p<0.001). The percentage of children who were described as being predominantly negative in mood decreased from 71% at BSL to 9% at PTR2, and the number of children who were described as predominantly positive increased from 29% at BSL to 86% at PTR2.

It should be noted that the level of positivity was significantly different between the C1 and C2 children at baseline t(20)=-3.568, p<0.01), where C1 children were reported to be exclusively negative in mood.

Advice only

A significant change was also seen following advice only (Z=2.2, p<0.03, ties 12) where initial results changed from 45% of children being predominantly negative to 75% being predominantly positive in mood.

(ii) Caregiver reports (Qualitative) (FORMS 9 and 10)

In response to the question *"What changes if any, do you see in your child (since we last saw you)?"* several comments were made in relation to improved overall mood.

> *"My child cries less."* (MUP10, PTR1)
>
> *"My child sleeps better."* (MUP16, PTR1)
>
> *"He's happy all the time because we talk to him more".* (CHC0407, PTR1)
>
> *"My child is much happier. When I call him he laughs. I'm really happy about this as he's not crying as much as before."* (CHC0101, PTR1)

3.2.5.4 Communication, interaction, participation (FORMS 9 and 10)

In response to the same question (*"What changes if any, do you see in your child?")* the greatest number of child changes reported relate to non-mealtime issues, especially the child's level of communication, interaction and participation. Comments included the child being less drowsy, more alert & lively; generally more responsive and interacting more; understanding more (words); talking / vocalising more; pointing for communication; playing more and participating in household chores.

> *"My child understands lots of things that she didn't before"* (MUP01, PTR1)
>
> *"We are bonding more than before"* (CDC02, PTR1)
>
> *"Now she makes sounds. She is less drowsy and more alert and lively than before."* (CHC0405, PTR1)

3.2.5.5 General mobility (FORMS 9 and 10)

The child's level of mobility was also reported on frequently, in answer to the same question, including comments on improvements in general mobility, increased upper limb mobility, head control and sitting balance.

> *"My child will sit when seated. He has got used to it".* (CDC01, PTR1)
>
> *"She is stronger now. She can sit in a way she couldn't before. If I put anything into her hand she can put it into her mouth"* (MUP16, PTR1)

Two caregivers (at both PTR1 and PTR2) reported that there had been no change, or a deterioration in their child's feeding since enrolling. Two caregivers reported there to be no more problems regarding feeding at PTR2.

3.2.6 Summary of outcomes

3.2.6.1 Quantitative data

The statistical significance of the quantitative results is outlined in table 3-24 below. (Data from observations are used rather than caregiver reports where possible). Significant results were achieved in all areas when analysing the overall change between BSL and PTR2. Change was achieved by PTR1 in all areas except for growth, and largely sustained to PTR2, following *advice plus training*. Significant change was observed in four of the thirteen outcomes following *advice only* (MUAC, frequency of reported chest-related illnesses, involvement in self-feeding and general mood).

Table 3-24 Summary of quantitative analyses: child outcomes

	Advice plus Training				Advice only	
	BSL-PTR1		BSL-PTR2		BSL-PAR	
Nutritional Status						
▪ WAZ(British 1990)	**N**	-	**Y**	*	**N**	-
▪ WAZ(CP 2006)	**N**	-	**N**	-	**N**	-
▪ MUAC raw scores	**N**	-	**Y**	**	**Y**	***
▪ MUACZ(CP 2006)	**N**	-	**N**	-	**N**	-
▪ BMIZ(British 1990)	**N**	-	**N**	-	**N**	-
Chest Health						
▪ Risk of aspiration – observed	**Y**	*	**Y**	*	**N**	-
▪ Frequency of chest-related illness - reported	**Y**	*	**Y**	**	**Y**	*
Child affect during feeding						
▪ Discomfort/distress during feeding – observed	**Y**	*	**Almost**	*p=0.059*	**N**	-
▪ Fussiness – reported	**Y**	**	**Y**	**	**N**	-
▪ Food refusal – reported	**Y**	**	**Y**	**	**N**	-
Child Feeding Skills						
▪ Maturity of oral feeding manner - observed	**Y**	**	**Y**	**	**N**	-
▪ Degree of oral spillage – observed	**Almost**	*p=0.06*	**Almost**	*p=0.06*	**N**	-
▪ Involvement in self-feeding - observed	**Y**	*	**Y**	*	**Y**	*
Additional Benefits						
▪ General mood – reported	**Y**	***	**Y**	***	**Y**	*

Key: Significance is summarised into three levels: $p \leq 0.05$ (*), $p \leq 0.01$ (**), $p \leq 0.001$ (***).

3.2.6.2 Qualitative data

The most commonly reported areas of positive child change in relation to mealtimes were improvements in child affect (improved mood and cooperation during mealtimes, decreased level of distress) and improvements in the ability to eat and drink (eating and drinking were ‘easier’, there was less oral struggle and the children were able to manage a greater range of foods and textures). Other positive changes included improvements in overall mood, communication, interaction, participation and general mobility.

3.3 Impact of the intervention on the caregiver

The impact of the intervention on the caregivers was assessed through carer stress levels (overall, and in relation to feeding) and time spent in feeding. Additional caregiver comments from open-ended questioning are also summarised.

3.3.1 Caregiver stress

Caregiver stress was assessed using a validated assessment tool as well as structured and open-ended interview questions.

3.3.1.1 **Overall stress** (SRQ20)

Scores from the SRQ20 (Harding *et al*., 1980) were used to assess overall mental well-being, however it was difficult to obtain scores consistently throughout the training and scores for only 16 C2 caregivers at BSL and PTR2 are complete. These reduced from a mean score of 10.4 (*SD* 5.23) at BSL to 7.42 (*SD* 5.82) at PTR2. Using a Paired Samples *t*-Test this difference was not found to be significant ($t(15)=1.64$, $p=0.12$).

3.3.1.2 **Stress with regard to the child's feeding difficulties** (FORMS 3, 9, 10, 11)

(i) Reported stress levels (Quantitative)

Caregivers rated their level of stress as *not al all* (0), *a little* (1), *somewhat* (2), *very* (3). The results are represented as mean scores below.

Table 3-25 Mean level of feeding-related stress reported by caregivers

	BSL	PTR1	PTR2
C1&C2	**2.8**	**1.4**	**0.7**
SD	*0.40*	*1.47*	*1.00*

	BSL	PAR
C2A	**2.9**	**2.5**
SD	*0.31*	*0.95*

Advice plus training

Using a Friedman Test an overall significant reduction in stress was observed (Chi-Square=23.77, $df=2$, $p<0.001$). A Wilcoxon Signed Ranks Test showed significance at PTR1 ($Z=3.28$, $p=0.001$) and PTR2 ($Z=4.00$, $p<0.001$). There was a reduction in the number of carers who said they felt *very* stressed, from 81% at BSL to 9% at PTR2.

Advice only

The reduction in stress was not significant following advice only ($Z=1.73$, $p=0.84$, ties 14).

(ii) Reported stress levels (Qualitative)

Results to questions (Q) asking carers how they felt about their child's feeding difficulties overall and how they felt during feeding itself are summarised below.

Q: *"In what way do your child's feeding problems bother you?"*

Answers were separated into themes or 'issues'. The number of total issues reported at each assessment point is summarised in the table below.

Table 3-26 Total number of issues reported

	BSL	PTR1	PTR2
C1 & C2	22	27	12

	BSL	PAR
C2A	21	30

Advice plus training

At PTR1, caregivers reported more concerns than at baseline assessment, however there was an overall 45% reduction in the number of concerns reported at PTR2.

Advice only

There was a small increase in the number of reported concerns following advice only.

Q: "*How do you feel during feeding?"*

The total number of negative feelings reported by caregivers was calculated and used as a measure of stress.

Table 3-27 Total number of negative feelings reported

	BSL	PTR1	PTR2
C1 & C2	50	21	28

	BSL	PAR
C2A	55	52

Advice plus training

Following advice plus training, the total number of negative feelings reported reduced from 50 to 28. In the same way, positive comments increased, with caregivers suggesting a strong sense of accepting the situation and worrying less about their children's feeding difficulties. There was marked decrease in comments relating to feeling annoyed or angry because feeding took a long time (the most frequently reported issues at BSL).

"Before I felt annoyed and angry during mealtimes but now I feel that if I feed my child in the new way, slowly he will improve. I don't feel annoyed or angry anymore." (CDC02, PTR1)

"Before, I felt really annoyed and I used to slap him. Now I feel good. I feel that if I continue in this way, he will be able to eat like other children". (MUP22, PTR1)

Advice only

The level of negative feeling reported remained unchanged following advice only.

3.3.2 Time spent in feeding

The length of assessed mealtimes was recorded and carers were asked at the end of the meal if it had been representative of usual mealtimes. The results reported below are derived from only those mealtimes which were considered representative. Results for the observations and reports are summarised together.

3.3.2.1 **Researcher observations** (FORM 7)

Table 3-28 Mean length of assessed mealtime (in minutes)

	BSL	PTR1	PTR2
C1&C2 (*n*=16)	**10.2**	**22.0**	**21.7**
SD	*3.41*	*10.89*	*9.39*

	BSL	PAR
C2A	**11.4**	**16.4**
SD	*6.54*	*7.05*

3.3.2.2 **Caregiver reports** (FORMS 3, 9, 10, 11)

Caregivers were asked how long mealtimes usually took: less than 30 minutes, 30-60 minutes or more than 60 minutes. The percentage of average meal lengths reported within each time category is presented in the table below and compared with the researcher observations (RO).

Table 3-29 Percentage average meal length (reported)

	BSL			PTR1			PTR2		
	<30 mins	30-60 mins	>60 mins	<30 mins	30-60 mins	>60 mins	<30 mins	30-60 mins	>60 mins
C1&C2	18	82	0	27	73	0	55	45	0
RO	100	0	0	81	19	0	81	19	0

	BSL			PAR		
	<30 mins	30-60 mins	>60 mins	<30 mins	30-60 mins	>60 mins
C2A	15	85	0	30	65	5
RO	95	5	0	100	0	0

Advice plus training

Observations:

Observed meal length doubled between the first assessment and the reviews, increasing from a mean of 10 minutes to a mean of 22 minutes at both PTR1 and PTR2 (rounded up to the nearest 1.0). Using a one factor within-subjects test of variance (ANOVA), this change was found to be significant ($F(2,30)=11.37$, $p<0.001$).

Analysed separately using a Paired Samples *t*-Test, significance was also observed at PTR1 ($t(15)=4.62$, $p<0.001$) and PTR2 ($t(15)=4.73$, $p<0.001$). Meal length at BSL ranged from 3-15 minutes and at PTR2, from 7-35 minutes, with 0% of meals at BSL and 20% of meals at PTR2 exceeding 30 minutes. As the number of meals given per day averaged at approximately five throughout the programme, observations suggest that 100% of C1 and C2 caregivers were spending less than 2.5 hours per day in feeding at BSL. This reduced to 81% at PTR2, with 19% spending between 2.5 and 5 hours in feeding.

Caregiver reports:

At first baseline, 82% of C1 and C2 caregivers reported mealtimes taking between 30 and 60 minutes. This reduced to 45% at PTR2. Using a Friedman Test, this reduction was found to be significant overall (Chi-Square=8.00, $df=2$, $p<0.05$), however, when analysed separately using a Wilcoxon Signed Ranks Test, significance was observed at PTR2 only (PTR1: $Z=0.71$, $p=0.48$, ties 14; PTR2: $Z=2.83$; $p=0.005$, ties 14).

Carer reports suggest that the majority (82%) were spending up to 5 hours per day in feeding at BSL. This reduced following training to 45%, with the remainder spending less than 2.5 hours per day in feeding.

Advice only

Observations:

Observed meal length increased by 31% between BSL and PAR. Using a Paired Samples *t*-Test this difference was found to be significant ($t(18)=-2.81$, $p<0.05$). Meals ranged from 3-35 minutes at BSL to 5-30 minutes at PAR. Although the mean length increased significantly, 100% of observed meals at PAR were less than 30 minutes in length, indicating that carers spent no more than 2.5 hours in feeding per day.

Caregiver reports:

At baseline the large majority of caregivers (85%) reported mealtimes taking between 30 and 60 minutes. This reduced to 65% at PAR with only 30% reporting meals to take less than 30 minutes. Using the Wilcoxon Signed Ranks Test, this change was found to be not significant ($Z=8.16$, $p=0.42$, ties 13). These reports indicate that the majority of carers were spending up to 5 hours per day in feeding.

Caregiver perceptions do not match researcher observations in this aspect of feeding, and in fact, run contrary to them. This is discussed in more detail in the Discussion chapter.

If the researcher observations are accurate, the outcomes with regards to mealtime length may be positive for the carers, not in reducing the length of mealtimes per se but rather in changing carers' perception of this.

3.3.3 Caregiver feedback

Carers were asked at the first review to comment on changes they had observed in themselves and their family since being involved in the programme and what changes (in their child, themselves or their family) they were happiest about as a result of the training. Answers to the questions are summarised below.

Q: *"What changes, if any, do you see in yourself?"* (FORMS 9 and 11)
Q: *"How do you feel now about feeding your child?"* (FORM 10)
The most commonly reported changes included carers feeling less worried and more optimistic regarding their child's feeding issues and feeling happier due to the improvements in their child's ability to feed and the reduction in difficulties. Other comments included feeling less annoyed about the difficulties and more accepting of them, improved interaction with their child and feeling happy due to the general positive changes in their child and their own sense of competence. Only one caregiver reported no reduction in negative feelings regarding or during feeding and one said they felt worse.

"I feel good because now when we're having our food he asks for food – and that makes me feel good. Before, I couldn't imagine my child would be able to eat rice and now I'm so surprised that he can." (MUP21 PAR)

"I feel good because my child has stopped vomiting when he eats because you advised me to sit my child up for feeding. And now he has less fever as a result and I feel good." (CDC03 PAR)

"Because I've been through the training I know how to feed her and how much to feed her….and I'm happy and she's happy…we're both happy". (MUP03, PTR1)

"I feel good. I understand that she will probably never be able to feed herself but she will be able to eat better." (SR01, PTR2)

"Now I know this is the reality it doesn't bother me." (CHC0402, PTR2)

Q: "*Have you observed any changes in the way the family behave towards you or yourself since you have been attending the groups?"* (FORM 9)
When asked, 50% questioned reported changes in the attitude of other members of the family following training. Almost 30% said that other members of the family were showing more interest in the child and in 25% of cases, they had showed interest in the training and had modified their feeding methods accordingly. Other comments included

other members of the family being happier with the child and less annoyed (due to the child's improvements), being more confident in the caregiver and her ability to look after the child and reports that the father was helping more.

> *"Because of the training… I had a conversation with my husband…. I told him about the training and then I told him this is our child and we have joint responsibility for her. Then he started sharing the jobs with me. Now my husband helps me do things like chopping the vegetables to make the curry. He asks me what I want him to do for the child."* (MUP10, PTR1)
>
> *"They are more interested in her and take her on their lap more because they see she is less sick now and more lively because of the training".* (CHC0405, PTR1)

Q: "*Overall, do you think the training programme was useful/are you satisfied? If so, in what way?"* (FORM 9)

Of those who were satisfied, the main reason given was that they had learnt so many things that would help their child. Other common themes included the improvements in child's feeding skills (reduced abnormal feeding behaviours and improved chewing, the improvements in the child's general abilities (especially their sitting ability) and that they could feed their child in more normal and convenient way (sitting up and/or using their hand). Less common themes were that the child could eat family food, was more responsive during feeding, and that the caregiver was no longer bothered by the feeding difficulties. Five caregivers were especially happy because they had received a level if service they had not previously experienced.

> *"I am happy with your programme. I have never seen a project like this before – you put a lot of effort into teaching us and I, and the other mothers learnt a lot of things."* (CHC0301, PTR1)
>
> *"If the training was ongoing it would be really helpful. If you could come to my house it would be especially helpful."* (CHC0101, PTR1)
>
> *"I liked your programme because before the training I was not aware of the damage I was causing her in my method of feeding her, and now I know better. And I'm happy about the positive response that I get from my daughter during mealtimes."* (MUP03, R1)

Q: "*Of all the changes, what changes are you happiest about?"* (FORM 9)

When asked what changes they felt happiest about, the most common themes were the improvements in their child's feeding abilities, that the child was happier and cooperating more during mealtimes, the positive changes in their own feeding methods, and the general improvements in the child.

3.3.4 Summary of impact on caregivers

3.3.4.1 Quantitative outcomes

The quantitative outcomes are summarised in the table below. Significance is categorised into three levels: $p \leq 0.05$ (*), $p \leq 0.01$ (**), $p \leq 0.001$ (***).

Table 3-30 Summary of outcomes for caregivers

	Advice plus training				Advice only	
	BSL-PTR1		BSL-PTR2		BSL-PAR	
Reported stress regarding feeding	**Y**	***	**Y**	***	**N**	-
Time spent feeding (observed increase)	**Y**	***	**Y**	***	**Y**	*
Time spent feeding (reported decrease)	**N**	-	**Y**	**	**N**	-

There were significant reductions in reported caregiver stress following *advice plus training* only. Perceived mealtime length had decreased following *advice plus training* however, significant increases were noted in observed mealtime length, following both.

3.3.4.2 Qualitative outcomes

Following training, there was a reduction in the number of issues concerning caregivers, who reported feeling generally less worried and more optimistic about their child's problems. They were happy with the improvements in their own feeding methods and with the improved feeding skills of their children. There was a reduction in the number of complaints about feeding taking a long time and there was a marked decrease in the amount of negative feeling towards the children during feeding. 54% of caregivers interviewed reported positive changes in the attitude and behaviour of other family members towards the child or caregiver.

All but two caregivers were satisfied with the training. The main reasons for satisfaction included the fact that they felt more equipped to help their child, the improvements in their child's feeding skills (reduced abnormal feeding behaviours & improved chewing), the improvements in their child's general abilities (especially their sitting ability) and that they could feed their child in more normal and convenient way (sitting up and/or using their hand).

3.4 Training outcomes

This section is divided into two parts. The first outlines changes in caregiver knowledge and the second, changes in caregiver feeding practices following intervention. The second addresses the areas of nutrition and hydration (including diet and overall responsiveness) and safety and sensitivity of feeding manner (including positioning, food consistency, utensil, sensitivity, responsiveness of feeding manner, and interaction style). Additional caregiver comments are given from open-ended interview questions.

3.4.1 Knowledge

Caregivers were assessed on their knowledge (FORMS 9 and 11) at PAR and PTR1 to see how much theory they had retained following *advice* and *advice plus training*. C1 and C2 caregivers could recall facts to a similarly high level at PTR1, scoring 11.7 (*SD* 1.32) and 10.8 (*SD* 1.47) respectively out of a potential 13 points. C2A caregivers, assessed at PAR, scored a mean of 6.95 points (*SD* 1.72). An Independent *t*-test revealed this difference to be significantly lower ($t(20)=8.56$, $p<0.01$) than the combined mean score for C1 and C2 at PTR1.

3.4.2 Behaviour change: nutrition and hydration

3.4.2.1 Providing a nutritious diet

As described in the Methods chapter, data pertaining to diet were collected through caregiver interview questions only, eliciting what food had been eaten in the last 24 hours and the frequency with which different food types were eaten over the past month. Data were summarised into the following food categories: vegetable (V), protein (P), milk or milk-based foods (M) and fruit (F). (Dal and eggs were the most common proteins consumed and bananas the most common fruit). As carbohydrate is contained within or alongside so many of the foods eaten and is of less nutritional value than the other food groups the results for carbohydrate intake were not analysed.

The calorific content of the food was assessed only in the question asking whether extra oil was added to the child's food since joining the training programme. It was not possible to estimate the oil intake from the other sources of data. The results are described below.

Table 3-31 Mean number of times each food type eaten per day

(The shading is used to aid reading of the table)

	BSL				PTR1				PTR2			
	V	P	F	M	V	P	F	M	V	P	F	M
C1&C2	1.2	1.5	1.0	3.1	2.2	2.3	1.2	2.7	1.5	2.0	1.2	2.5
SD	*1.38*	*1.45*	*1.19*	*2.01*	*1.86*	*1.24*	*1.29*	*2.04*	*1.67*	*1.59*	*1.50*	*1.98*

	BSL				PAR			
	V	P	F	M	V	P	F	M
C2A	1.3	1.7	1.2	3.4	1.5	1.9	1.1	3.3
SD	*1.49*	*1.56*	*1.66*	*2.38*	*1.45*	*2.04*	*1.32*	*2.52*

Key: vegetable (V), protein (P), milk or milk-based foods (M) and fruit (F)

Table 3-32 Percentage of caregivers reportedly giving extra oil as a result of training

	PTR1	PTR2
C1&C2	79	58

	PAR
C2A	30

Caregivers were asked if availability of food for their child had been an issue over the past month. The results are summarised in the table below.

Table 3-33 Percentage of carers reporting problems of food availability in the past month

	BSL	PTR1	PTR2
C1&C2	14	36	32

	BSL	PAR
C2A	25	65

(The data were analysed using non-parametric tests due to abnormal distribution).

Advice plus training

Using a Friedman Test, an overall significant increase was found in the number of times vegetables and protein were given. (Vegetables: Chi-Square=7.44, *df*=2, $p<0.05$; Protein: Chi-Square=6.82, *df*=2, $p<0.05$;) and at PTR1, C2 carers were also giving 30% more fruit. A Wilcoxon Signed Ranks Test showed these changes to be significant at PTR1 (Vegetables: $Z=2.29$, $p<0.05$; Protein: $Z=2.38$, $p<0.05$) but change at PTR2 was not significant (Vegetables: $Z=1.533$, $p=0.53$; Protein: $Z=1.03$, p=0.30) due to lack of compliance in the C1 cohort. C2 carers maintained their progress in levels of vegetables and protein given but not in fruit.

Using a Friedman Test, the target of a decreased frequency of milk-based foods did not achieve significance (Chi-Square=2.49, *df*=2, $p=0.29$) and changes in fruit intake at PTR1 were also not significant (Chi-Square=3.92, *df*=2, $p=0.14$).

At PTR1, 79% of C1 and C2 caregivers reported adding extra oil to their child's food since attending the training. This reduced to 58% at PTR2. Compliance was greater amongst the C2 cohort, whereby 75% C2 carers as opposed to 40% of C1 carers reported giving extra oil at PTR2.

Food availability was an issue for more than 30% of the C1 and C2 children at PTR1 and PTR2 as opposed to only 14% at baseline.

Advice only

A Wilcoxon Signed Ranks Test showed no observable improvements in diet following *advice only* (Vegetables: Z=0.53, p=0.59; Protein Z=0.196, p=0.84; Fruit: Z=0.05, p=0.96; Milk: Z=0.22, p=0.83). 30% of C2A caregivers did report giving extra oil however. Food availability was reported as an issue at both assessments but more so at PAR, increasing from 25% to 65% of children being affected.

Factors affecting compliance:

- The most common reasons reported by caregivers for non-compliance with regards to diet were that the children refused new food or for financial reasons (FORMS 8a and 9).
- Food availability may have impacted negatively on the outcomes (especially in the outcomes for the C2A group), which reportedly affected the quality of the food carers could give, rather than quantity.

3.4.2.2 Responsive feeding practices

(i) Feeding frequently and in response to hunger (FORMS 3, 9, 10, 11)

Carers were asked how many meals they gave their child per day and whether they fed their child if it showed signs of hunger. The results are summarised below.

Table 3-34 Mean number of meals given per day

	BSL	PTR1	PTR2
C1&C2	**5.1**	**5.5**	**5.2**
SD	*1.52*	*1.54*	*1.59*

	BSL	PAR
C2A	**5.5**	**5.2**
SD	*2.33*	*1.64*

Table 3-35 Percentage of caregivers who fed their child at signs of hunger

	BSL	PTR1	PTR2
C1&2	50	80	83

	BSL	PAR
C2A	55	80

Advice plus training

Children were given, on average, five meals per day. This was consistent across all groups and did not change after training (which recommended six meals per day). In terms of responding to their child's hunger, a Cochran Test showed overall significant improvements following training (Q=7.00, df=2, p<0.05). Using a McNemar Test, the degree of change achieved at PTR1 was observed to be significant (p<0.05) but not quite at PTR2 (p=0.07).

Advice only

Likewise, the number of meals given per day did not change. There was an improvement in responsiveness to hunger following *advice only*, however, the degree of change was not statistically significant (p=0.13).

The average number of meals given per day was the same across all groups and did not change over time, however it was close to the recommended number of six.

(ii) Giving enough food (FORMS 3, 9, 10, 11)

The quantity of food given to the child was only calculated for food which was fed from a bowl or bottle (ie. not finger food). Quantity was estimated by carers indicating how full the bowl/bottle had been at each meal during the 24 hour food recall section of the interview. This was then converted into the equivalent in millilitres (ml).

Table 3-36 Mean food intake in ml

	BSL	PTR1	PTR2
C1&C2 (*n*=19)	**821.1**	**922.7**	**880.8**
Min-max	245-1575	375-1600	105-1700
SD	*413.02*	*354.56*	*424.05*

	BSL	PAR
C2A (*n*=19)	**995.0**	**998.1**
Min-max	245-3000	100-3000
SD	*616.84*	*608.61*

Advice plus training and Advice only

Analysis of the data showed no significant changes over time. The mean quantity of food given to the children in all of the groups was approximately 1000ml per day, or less, at all stages of the programme.

Factors affecting compliance:

- Carer reports indicated that sickness may have had a temporary impact on food intake, but this was taken into account when interviewing and would not have affected the results overall.
- The reason stated by caregivers for not increasing the number of meals given per day was that the children were not hungry enough to eat more often or that the caregiver was too busy and there was no one else knew how to feed the child. (FORMS 8a and 9).

(iii) Giving enough to drink (FORMS 3, 9, 10, 11)

Fluid intake was measured through caregiver estimates of amount of drink consumed in a day (using the receptacle used at home) and calculating the equivalent in millilitres. The fluid content of the food was not calculated, as accurate ways of measuring this were not available. Potential inaccuracies in calculation of drinks include the variations in the reliability of caregiver reports as well as the difference between what was given and what was actually consumed (and not lost through oral spillage). The results are illustrated in the table below.

Table 3-37 Approximate mean fluid intake through drinks (ml)

	BSL	PTR1	PTR2
C1&C2 *n*=21	**173.7**	**361.9**	**300.2**
Min-max	0-375	25-850	20-1000
SD	*107.48*	*193.60*	*218.33*

	BSL	PAR
C2A	**212.2**	**270.3**
Min-Max	20-1000	50-750
SD	*208.90*	*206.81*

(As the data are not normally distributed, non-parametric tests were used for analysis).

Advice plus training

Using a Friedman Test, an overall significant increase in the quantity of drinks given following *advice plus training* was observed. (Chi-Square=9.44, *df*=2, p<0.01). A Wilcoxon Signed Rank Test showed this increase to be significant at PTR1 (*Z*=3.47, *p*=0.001) and PTR2 (*Z*=2.71, *p*<0.01).

Advice only

There was a small increase in the quantity of drinks being given at PAR however this was not significant (*Z*=1.83, *p*=0.07).

Factors affecting compliance:

- Giving drinks was one of the biggest sources of concern for caregivers, and one of the aspects of 'feeding' they found the hardest, due to the enormous physical difficulty their children experienced with it.
- Again, quantity given would have been limited by the children's ability to manage drinks as well as caregiver skill and awareness.
- Reasons given for lack of positive change in this area are summarised as follows (FORMS 8a, 9): -

  -The child didn't want to drink

  -The child couldn't manage the quantity

  -Lack of caregiver time

  -The caregiver didn't regard it as an issue

(iv) Providing positive verbal encouragement (FORM 7)

As described in Chapter 2 this behaviour is also referred to as 'positive verbal proactiveness' and is considered an important factor in aiding adequate food intake in children. An overall score of positive verbal proactiveness was awarded at the end of each mealtime observation from a 5-point rating scale of *never* (0), *less than 25% of the time* (1), *approximately 50% of the time* (2), *approximately 75% of the time* (3), *100% of the time* (4).

Table 3-38 Mean positive verbal proactiveness (Maximum potential score of 4)

	BSL	PTR1	PTR2
C1&C2 *n*=21	**1.0**	**3.0**	**2.5**
SD	*1.24*	*1.14*	*1.44*

	BSL	PAR
C2A *n*=20	**1.2**	**1.6**
SD	*1.23*	*1.40*

Advice plus training

Using a Friedman test, an overall significant increase in positive proactiveness was observed following *advice plus training* (Chi-Square=20.06, *df*=2, $p<0.001$). A Wilcoxon Signed Ranks Test showed the increase to be significant at PTR1 and PTR2 (PTR1: $Z=3.65$, $p<0.001$; PTR2: $Z=2.89$, $p<0.005$)

Advice only

Positive proactiveness also increased after *advice only* but not to a significant degree ($Z=1.09$, $p=0.28$)

Factors affecting compliance:

The main reasons caregivers gave for non-compliance were that they did not like talking during feeding and were not used to it.

3.4.2.3 Summary of outcomes for nutrition and hydration

According to the measures used, there was no apparent change in the amount of food given following *advice only* or *advice plus training* either in quantity per mealtime or number of meals per day. Significant changes were observed in other areas following *advice plus training* however. Significant qualitative improvements were made to the dietary content of the food (vegetables and protein), resulting in children receiving a more similar range of food types to the other family members. Adding oil to the diet and providing verbal encouragement were well complied with. Although the number of meals given per day remained the same, significantly more caregivers reported feeding their children when they were hungry.

Fluid intake improved significantly in all groups, including following *advice only*, although levels remained clinically insufficient.

3.4.3 Behaviour change: safety and responsiveness of feeding manner

3.4.3.1 Safe positioning (FORM 7)

(i) Trunk position

Children were recorded in four main positions: *lying (90°), breastfeeding (90°-45°), semi-reclined (45°)* and *upright (45°-0°).* Lying and breastfeeding present the greatest risk of aspiration and allow for least oral mobility and involvement in self-feeding. Desirable positions are therefore being fed at 45° or fully upright. The scores in the table below represent the percentage of children observed in any of the positions during the observed mealtimes. (Although children remained predominantly in one position during feeding, some children were observed in more than one position during the same mealtime). Recordings for lying and breastfeeding and likewise, for semi-reclined and upright, have been combined in the table below and the columns therefore represent undesirable (shaded column) versus desirable positioning.

Table 3-39 Percentage of children observed in each position at some point during the assessed mealtime

C1&C2	BSL		PTR1		PTR2	
	Lying/ Breast-feeding	45° /upright	Lying/ Breast-feeding	45° /upright	Lying/ Breast-feeding	45° /upright
Food	79	26	4	100	14	100
Drink	84	22	10	100	19	100

C2A	BSL		PAR	
	Lying/ Breast-feeding	45° /upright	Lying/ Breast-feeding	45° /upright
Food	55	50	25	70
Drink	65	45	25	90

As the figures for food and drink were very similar, they were combined for the statistical analysis.

Advice plus training

A Friedman Test showed the overall number of children being fed, at any time, in lying or breast-feeding to reduce significantly (Chi-Square=23.41, *df*=2, $p<0.001$) from 82% to 7% and 17% at PTR1 and PTR2 respectively. When analysed separately using the Wilcoxon Signed Ranks Test, the results at PTR1 and PTR2 were both highly significant (PTR1: $Z=3.87$, $p<0.001$; PTR2: $Z=3.742$, $p<0.001$).

The overall number of children observed, at any time, at 45° or in upright position rose from 24% to 100% at both PTR1 and PTR2. Again, this result was significant overall

(Chi-Square=32.00, *df*=2, *p*<0.001) and at both PTR1 and PTR2 (PTR1: *Z*=4.00, *p*<0.001; PTR2: *Z*=4.00, *p*<0.001).

Advice only

Unsafe positioning decreased to a significant degree (*Z*=2.45 *p*<0.05, ties 14) following *advice only*, although two children were still being observed in lying position for eating, and one for drinking, at PAR. Positive positioning also increased significantly overall (*Z*=2.33; *p*<0.05, ties 11) with greater changes achieved when giving drinks than food.

Factors affecting compliance:

Data from interviews suggest that the most common reason for non-compliance with regards to maintaining an upright trunk position (in the lap) was that it became tiring to maintain (FORMS 8a and 9).

(ii) Head position

Four main head positions were recorded: *very extended (90°-45°), slightly extended (45°-0°), upright* and *flexed (0°-45°).* Being given food or drinks with the head in extension poses children at the greatest risk of aspiration, with fluids posing a higher risk than solids. Desirable head positions are therefore *upright* or *flexed.* The scores in the table below represent the percentage of children observed in any of the position during the observed mealtimes. Recordings for *very* and *slightly extended* and likewise, for *upright* or *flexed*, have been combined in the table below, and the columns therefore represent undesirable (shaded column) versus desirable head positioning.

Table 3-40 Percentage of children observed in each position at any time during the assessed mealtimes

C1&C2	BSL		PTR1		PTR2	
	Extended	Upright / flexed	Extended	Upright / flexed	Extended	Upright / flexed
Food	100	36	96	55	86	68
Drink	100	18	77	46	83	41

C2A	BSL		PAR	
	Extended	Upright / flexed	Extended	Upright / flexed
Food	100	40	100	65
Drink	65	45	25	90

Advice plus training

At BSL, 100% of the children were observed with their heads in extension (for food and drink) at some point during the assessed mealtime. Observations of head in straight or flexed positions were observed a third of the time or less.

FOOD:

Using a Friedman Test, scores for head in extension did not change significantly (Chi-Square=3.50, *df*=2, *p*=0.17) however, there was a significant increase in the number of children observed in positive positioning following *advice plus training* (Chi-Square=8.22, *df*=2, p<0.05), which, although, using a Wilcoxon Signed Ranks Test was not shown to be significant at PTR1 (*Z*=1.63, *p*=0.10, ties 16), was significant at PTR2 (*Z*=2.65, *p*<0.01, ties 15).

DRINK:

Using the same tests, scores for head in extension were observed to decrease significantly following *advice plus training* (Chi-Square=6.00, *df*=2, *p*=0.05). This was significant at PTR1 (*Z*=2.24, *p*<0.05, ties 17) and PTR2 (*Z*=2.00, *p*<0.05, ties18). Although improvements were observed in positive positioning, these were not significant (Chi-Square=4.43, *df*=2; *p*=0.11).

Advice only

A Wilcoxon Signed Ranks Test showed no significant changes in head positioning for giving food in this group (*Extended:* Z=0.00, *p*=1.00; *Upright/Flexed: Z*=1.51; *p*=0.13) however positioning for drinks improved significantly both in terms of reduction in negative positions and increases in positive positioning (*Extended: Z*=2.83, *p*=0.005, ties 12; *Upright//Flexed: Z*=2.71, *p*<0.01).

(iii) Use of adapted seating for feeding

Use of the special seats provided to participants, or which they already owned, was recorded during the mealtime observations. The percentage of children observed being given food (F) and drinks (D) in these seats is summarised in the table below.

Table 3-41 Percentage use of adapted seat for feeding (observed)

	BSL		PTR1		PTR2	
	F	D	F	D	F	D
C1&C2	0	0	41	27	14	14

	BSL		PAR	
	F	D	F	D
C2A	0	0	25	16

Advice plus training

FOOD: There was a 41% compliance with the use of adapted seating for food at PTR1 which reduced to 14% at PTR2. Using a Cochran Test this change was shown to be significant overall (Q=12.60, df=2, p<0.005). When analysed separately, a McNemar Test showed significance at PTR1 (p<0.005) but not at PTR2 (p=0.25).

DRINK: Compliance was lower with regards to using the adapted seat for giving drinks, however the overall result was significant (Q=6.75, df=2, p<0.05). Again, significance was achieved at PTR1 (p<0.05) but not at PTR2 (p=0.25)

Advice only

Compliance with the use of the adapted seat for giving food following *advice only* was almost significant (p=0.06) but not for giving drinks (p=0.25).

Factors affecting compliance:

Compliance was greater when giving food than drink. This was in part due to the difficulty in achieving appropriate head positioning using the adapted seats and carers' awareness of the particular importance of this for drinks.

Reasons given for non-compliance in this area were as follows (FORMS 8a and 9):

- It was difficult to achieve and maintain a good head position in the seat.
- The upright position increased oral spillage.
- The child got irritable in the chair / moved around / their body extended.
- The child seemed happy on the floor and therefore cooperated more with feeding.
- It took too long to put the child in the chair.
- There was not enough space in house to keep the chair.
- The seats became damaged through rain water and so could no longer used.

The seats were however used outside feeding times. 68% of C1&C2 caregivers said they used the chair at other times other than for feeding.

3.4.3.2 Appropriate food consistency (FORM 7)

Food was divided into six categories of consistency for scoring, adapted from the categories described by Winstock (1994) and in accordance with the range of consistencies observed. The categories were as follows: *thin liquid* (eg. water), *thick liquid* (eg. suji or runny yoghurt), *puree* (eg. Cerelac or baby food), *soft-solid* (eg. khichuri or mashed vegetables), *easy-to-bite solid* (eg. papaya or melon) and *chewy solid* (eg. rice and chewy curry). Thin liquids, easy-to-bite solids and chewy solids were never or rarely observed and so for the purpose of analysis, the six categories were

reduced to three: *thick liquid, puree* and *soft-solid*. As more than one consistency was occasionally observed during a mealtime observation the percentages in the table below represent the number of times foods within a given category were observed at any time during the assessment. Statistical analyses were performed in a similar way to that for the different trunk and head positions, comparing the frequency with which each category was observed at each time point.

Table 3-42 Percentage of children observed eating foods in each category at any point in the assessment

	Thick liquid			Puree			Soft-solid		
	BSL	PTR1	PTR2	BSL	PTR1	PTR2	BSL	PTR1	PTR2
C1&C2	29	0	0	52	33	33	19	67	67

	Thick liquid		Puree		Soft-solid	
	BSL	PAR	BSL	PAR	BSL	PAR
C2A *n*=21	32	20	42	50	25	30

Whether the food was of a mixed consistency or homogenous was also noted, as homogeneity was a recommendation for safer feeding. The results are summarised in the table below.

Table 3-43 Percentage of food observed to be homogenous

	BSL	PTR1	PTR2
C1&C2	57	76	57

	BSL	PAR
C2A *n*=21	80	65

A general trend was observed towards the children eating food of a thicker consistency (which is safer and more generally nutritious than liquid food) although none of the children progressed onto easy-to-bite or chewy solids. By PTR1, none of the children were being given food in liquid form.

Advice plus training

Using a Cochran Test, a significant overall decrease was observed in the frequency with which foods were given in liquid form (Q=12.00, df=2, p<0.005). A McNemar Test showed significant change achieved by PTR1 (p<0.05) which was sustained to PTR2 (p<0.05).

The increased frequency with which soft-solid foods were given was also significant (Q=15.39, df=2, p<0.001) with significant change occurring at PTR1 (p<0.01), sustained to PTR2 (p<0.005). The frequency with which purees was given did not change significantly (Q=2.29, df=2, p=0.32). Changes in homogeneity were not

significant overall (Q=2.909, df=2, p=0.234,) nor was the considerable increase at PTR1 significant (p=0.289).

Advice only

A McNemar test showed the slight changes in consistency following *advice only* not to be significant. (Liquid: p=0.5; puree: p=0.63; soft-solid: p=1.00). Homogeneity decreased between BSL and PAR, which was therefore a negative result.

Factors affecting compliance:

- The relationship between oral skills and food consistency (see Methods chapter p88) means that the degree of progress in giving foods of more solid consistency would have been limited by the development in the children's oral skills, required to manage this change. It should be noted that with children of such a severe degree of physical limitation, few would be expected reach the stage of chewing solid food.

- Progress would have been further influenced by the age of the child, whereby younger children accept solid foods more readily than older children (Northstone *et al.*, 2001).

- Reasons reported by caregivers for non-compliance with regards to increasing food consistency included not remembering the importance of giving more solid food and finding the runnier food easier to give. (FORMS 8a and 9).

- The results for improving homogeneity are poor. One reason for this may have been the increase in more solid foods being given and the greater difficulty achieving homogeneity in this. Several caregivers reported problems in being able to leave rice to boil for long enough for it to become soft, which is necessary for the food to be homogenous. This was particular issue for mothers who were sharing a cooker with various other families or else it took too long the wood-burner stove which was slow. (FORMS 8a and 9).

3.4.3.3 **Use of appropriate utensil** (FORM 7)

For the purposes of reporting, utensils were classified as appropriate or inappropriate. The table below illustrates which utensil belongs to which category.

Table 3-44 Classification of appropriate versus inappropriate utensils

	Appropriate	Inappropriate
Food	Hand Metal/plastic teaspoon	Dessert spoon Chinese soup spoon Feeder bottle
Drink	Teaspoon Short beaker/glass Teacup Trainer without lid	Feeder bottle Tall glass Dessert spoon Trainer with lid

The percentage of inappropriate utensils observed in the assessed mealtimes is illustrated in the table below. Scores for food and drink utensils are combined.

Table 3-45 Percentage usage of inappropriate utensil

	BSL	PTR1	PTR2
C1&C2	**35**	**4**	**9**

	BSL	PAR
C2A	**33**	**17**

Advice plus training

A Cochran Test was used to analysis of the frequency of inappropriate utensils used at any time during assessed mealtimes, which revealed an overall significant decrease in inappropriate utensils (Q=14.00, df=2, p=0.001). This change was observed, using a McNemar Test, to be significant both at PTR1 and PTR2 (PTR1: p<0.005; PTR2: p<0.05).

Advice only

The decrease in inappropriate utensils was also significant for the C2A group (p<0.05).

The researcher is aware that one utensil may be more appropriate than another, depending on the child's needs, and such a standard scoring system does not account for this. Nonetheless, this simple categorisation is sufficient to demonstrate an overall trend.

Factors affecting compliance (FORMS 8a and 9):

Reasons given for non-compliance in this area included the following.

- The melamine spoon provided in training was broken, lost or taken away by a younger child to play with.
- A metal teaspoon was used rather than the melamine one as it was smaller and therefore easier for the child to manage orally.
- A tall glass was used rather than the small beaker or spoon that was provided because the caregiver could give more drink that way.
- The caregiver had forgotten why the small cup was important.

- The caregiver gave drinks from the same mug that she used herself as it was more practical.
- The feeder bottle continued to be used to ensure that the child fed well.

3.4.3.4 **Sensitivity** (FORMS 3, 9, 11)

Sensitivity refers to a caregiver's ability to read their child's cues. Caregiver sensitivity was measured using the following three questions. (The questions were not asked again at PTR2 due to constraints of interview length).

1a."Do you know when your child is hungry?" 1b." If so, how do you know? What does your child do?"

2a. "Do you know when your child is ready for the next mouthful?" 2b." If so, how do you know? What does your child do?"

3a. "Do you know when your child wants to stop?" 3b." If so, how do you know? What does your child do?"

If the answer to the first part of each question was yes, a point was awarded. Another point was awarded for each behaviour reported. The maximum number of behaviours listed by caregivers was two and so the maximum possible score of sensitivity was 9 points. The mean scores are outlined in the table below.

Table 3-46 Mean score of sensitivity (maximum potential score of 9)

	BSL	PTR1	PTR2
C1&C2	**3.8**	**5.4**	
SD	*1.31*	*1.36*	

	BSL	PAR
C2A	**4.2**	**4.6**
SD	*1.40*	*1.28*

Advice plus training

A Wilcoxon Signed Ranks Test revealed a significant increase in observed caregiver sensitivity between BSL and PTR1 (Z=3.19, p=0.001).

Advice only

There was no significant change in sensitivity after advice only (Z=1.12, p=0.27).

3.4.3.5 **Responsiveness of feeding manner** (FORM 7)

Caregivers scored 0 if *amount per mouthful* and *pacing* were identified as a training need. They scored 1, if only one or the other was identified, and scored 2 if neither was identified. Scores for responsiveness with regards to giving food and drink are combined and summarised below.

Table 3-47 Mean responsiveness of feeding manner (maximum potential score of 4)

	BSL	PTR1	PTR2
C1&C2 *n*=21	**1.3**	**2.4**	**2.9**
SD	*1.01*	*0.75*	*0.10*

	BSL	PAR
C2A	**1.3**	**1.5**
SD	*1.2*	*1.12*

Advice plus training

Using a Friedman Test, change was shown to be significant overall (Chi-Square=20.01, *df*=2, *p*<0.001). Significance was also observed, using a Wilcoxon Signed Ranks Test, at both PTR1 and PTR2 (PTR1: *Z*=3.23; *p*=0.001; PTR2: *Z*=3.44, *p*=0.001).

It should be noted that C2 carers were significantly more responsive in feeding manner than C1 carers at baseline (*t*(20)=2.88, *p*<0.01).

Advice only

There was no significant change following advice only (*Z*=0.78, *p*=0.43).

Factors affecting compliance (FORMS 8a and 9):

Reasons given for lack of positive change in the area of responsive feeding manner include the following.

- Not regarding the advice as important.
- The caregiver being habituated and forgetting to change technique.
- The child being habituated and not wanting to change.
- The caregiver being in a hurry.

3.4.3.6 Minimising negative interaction

As described in Chapter 2, this behaviour is also referred to as negative proactiveness. Negative proactiveness is further divided up into negative verbal and negative physical proactiveness.

The scores were derived from combining caregiver reports (FORM 3, 9, 10, 11) with researcher observations (FORM 7). Answers to the question, 'Do you verbally force your child to eat?' or 'Do you physically force your child to eat?' (*never* (0), *sometimes* (1), *always* (2)), were combined with the 5-point frequency rating of *never* (0), *less than 25% of the time* (1), *approximately 50% of the time* (2), *approximately 75% of the time* (3), *100% of the time* (4), scored during the mealtime observation, giving a maximum

possible score of 6. Mean scores for negative verbal and physical proactiveness are summarised in tables 3-48 and 3-49 below.

Table 3-48 Mean negative verbal proactiveness (maximum potential score of 6)

	BSL	PTR1	PTR2
C1&C2	**1.1**	**0.6**	**0.8**
SD	*0.75*	*0.96*	*1.10*

	BSL	PAR
C2A	1.4	1.3
SD	*1.23*	*0.85*

Table 3-49 Mean negative physical proactiveness (maximum potential score of 6)

	BSL	PTR1	PTR2
C1&C2	**2.3**	**0.3**	**0.6**
SD	*1.64*	*0.55*	*0.85*

	BSL	PAR
C2A	**1.9**	**1.3**
SD	*1.27*	*1.13*

Advice plus training

Levels of physical negativity started at a higher level and reduced to a greater extent than verbal negativity at PTR1, resulting in similar levels between the two at PTR2. Using a Friedman Test, the overall reduction in negative verbal proactiveness was shown to be almost significant (Chi-Square=5.72, *df*=2, *p*=0.06). Reductions in negative physical proactiveness were significant overall (Chi-Square=28.63, *df*=2, *p*<0.001). Significance was also observed, using a Wilcoxon Signed Ranks Test at each review (PTR1: *Z*=3.90, *p*<0.001; PTR2: *Z*=3.50, *p*<0.001).

Advice only

There were no significant changes to negative interactions following advice only (*Negative verbal: Z*=0.51, *p*=0.61, ties 13; *Negative physical: Z*=1.84; *p*=0.07)

Factors affecting compliance:

The most common reasons given for non-compliance in this area were as follows.

- Needing to force the child to eat when their child was sick and did not want to eat.
- Needing to force their child to eat because the caregiver knew they were hungry.
- Stopping only when food was finished as the child needed the nutrition.
- Forcing the child to finish food because the caregiver did not want to waste it.

This issue is discussed in Chapter 4.

3.4.3.7 Summary of outcomes for safety and responsiveness of feeding manner

Positioning

- Caregivers were successful in changing the overall position in which they fed their children for the majority of the time.
- Some significant changes were made to head positioning, particularly when giving drinks, but this remained problematic.
- Improvements were seen in both head and trunk positioning following *advice only* but to a lesser degree than following *advice plus training*.
- Compliance with regards to the use of adapted seating for feeding was significant at PTR1 but not sustained.

Consistency and utensil

- Significant results were achieved in providing food of thicker consistencies and the use of appropriate of utensils.

Responsiveness and Interaction style

- Significant changes were seen in caregiver sensitivity, responsiveness to cues and appropriate interaction style following *advice plus training*.

Following *advice only*, significance was only achieved with regards to the appropriate use of utensils.

3.4.4 Behaviour change: caregiver perception

Carers were asked to comment on what changes they had made in their feeding practices since receiving training. Questions included:

Q: *"Have you been able to do all the things we taught you to do in the training? What were you able to do?"* (FORM 9)
Q: *"What changes, if any, do you see in how you are feeding your child?"* (FORM10)

Most responses relate to the caregiver talking more to the child in preparation for and during feeding.

> *"From the training I know I need to prepare this child and talk to her before feeding her. Before, I didn't know and I gave her food before she was ready and she was shocked, but I carried on giving her food that way."* (MUP05, PTR1)

Other responses relate to improvements in food preparation, being more responsive overall (eg. noticing that the child needs more drink), being more patient during feeding, feeding in a more sensitive and responsive manner, and interacting less negatively.

> *"I'm more careful about making hichuri. I make sure it has lots of vegetables in it – more so than before. I feed him in a quiet place. I finish my work first so I'm not in a hurry to feed and tell people to go away. I stop the TV and then I feed my child."* (CDC02, PTR1)
>
> *"Due to your advice I changed what I was doing and my child changed."* (MUP21, PTR1)
>
> *"She used to drink a small amount only but now I notice my child looking at water so I give him more. I used to only give it at mealtimes because I didn't realise she should have more."* (MUP22, PTR1)
>
> *"(He now wants to eat) because I try to give him food he likes. Before, I just used to get annoyed but now I have more patience. Before I fed him with his head back and maybe it was difficult for him to swallow, and that's why he didn't want to eat*." (MUP22, PTR1)
>
> *"I'm trying to teach him to feed himself and I believe that he will be able to feed himself in the future. And I hope that if he feeds himself he will eat more."* (CHC0402, PTR1)
>
> *"Before, I fed my child the wrong way. Now I feed him the right way and now he eats nicely. He's not spilling a lot because I'm giving small mouthfuls"* (MUP12, PTR1)
>
> *"He used to cry when I fed him because I wad feeding him the next mouthful before he's finished the previous one. Now I feed him a small amount and slowly and wait until the previous mouthful is finished before I give the next one. I learnt it from you. I used to force him and get angry but I don't anymore. I just feed him in a normal way now."* (CDC02, PTR2)
>
> *"I don't beat her like before. When she wants to stop I just stop and lie her down. I don't force her. I don't get angry and yell at her."* (MUP01, PTR2)

3.4.5 Summary of training outcomes

3.4.5.1 Quantitative data

The analyses from the quantitative data are summarised in the table 3-50 below.
(Note: Trunk positioning is combined for food and drink as the scores were similar for both. As the scores for head positioning were different for food and drink, these are reported separately. Outcomes for consistency are repeated as they pertain to more than one aspect of feeding).

Summary:

Advice plus training resulted in significant changes in caregiver feeding practices in all areas except for some aspects of head positioning and achieving increased homogeneity of food consistency. Changes were not sustained to a level of significance in the areas of diet and feeding in response to hunger.

Advice only resulted in fewer significant changes in caregiver behaviour. Significance was achieved in the areas of positioning of the trunk for eating and drinking, positioning of the head for drinking and use of appropriate utensil.

3.4.5.2 Qualitative data

The most frequent change reported by carers was the increase in verbal encouragement given before and during feeding. Other areas of reported change cover the whole range of areas taught.

Table 3-50 Summary of quantitative analyses: training outcomes

	Advice plus Training				Advice only	
	BSL-PTR1		BSL-PTR2		BSL-PAR	
Ensuring adequate nutrition & fluids						
▪ Preparation of nutritious food ↑ *vegetables*	**Y**	*	**N**	-	**N**	-
↑ *protein*	**Y**	*	**N**	-	**N**	-
▪ Feeding in response to hunger	**Y**	*	**N**	-	**N**	-
▪ Giving enough food	**N**	-	**N**	-	**N**	-
▪ Giving enough to drink	**Y**	***	**Y**	**	**N**	-
▪ Giving verbal encouragement	**Y**	***	**Y**	**	**N**	-
▪ Food consistency ↓ *liquid*	**Y**	*	**Y**	*	**N**	-
↑ *solid*	**Y**	**	**Y**	**	**N**	-
Safe & responsive feeding practices						
▪ **Trunk** positioning ↓ *lying/ breastfeeding*	**Y**	***	**Y**	***	**Y**	*
↑ *45° / upright*	**Y**	***	**Y**	***	**Y**	*
▪ Head positioning (Food) ↓ *extended*	**N**				**N**	-
↑ *straight / flexed*	**N**	-	**Y**	**	**N**	-
(Drink) ↓ *extended*	**Y**	*	**Y**	*	**Y**	**
↑ *straight / flexed*	**N**			-	**Y**	**
▪ Food consistency ↓ *liquid*	**Y**	*	**Y**	*	**N**	-
↑ *solid*	**Y**	**	**Y**	**	**N**	-
↑ *homogeneity*	**N**			-	**N**	-
▪ Appropriate utensil	**Y**	**	**Y**	*	**Y**	*
▪ Sensitivity to cues	**Y**	***			**N**	-
▪ Responsive manner (amount per mouthful & pacing)	**Y**	***	**Y**	***	**N**	-
▪ Minimising negative interaction & forcing (V)	**N**			-	**N**	-
(P)	**Y**	***	**Y**	***	**N**	-

Key: Statistical significance is summarised into three levels: $p \leq 0.05$ (*), $p \leq 0.01$ (**), $p \leq 0.001$ (***).

3.5 Clinical Effectiveness

The commentary of results in the previous sections has reported specific outcomes relating to the children, the caregivers and the training, with the level of significance determined using statistical analyses. As this was a clinical intervention study, it is also important to report on the clinical effectiveness or 'clinical significance' of the interventions. The measurement of this is outlined below.

As part of the intervention, individual training targets were set in accordance with the clinical needs of each child, the ultimate aim being the achievement of an appropriate (ie. safe and responsive) caregiver feeding style for each. Following observation, intervention aims and areas of training need were identified for each child-caregiver pair and subsequent targets with respect to caregiver feeding practices were set (FORM 8). A different number of target areas were identified for each caregiver according to observed need. Using this system allowed the investigators to evaluate caregiver behaviour change in terms of clinical appropriateness and thus modify their advice accordingly as well as score change in terms of clinical effectiveness, or 'clinical significance'.

Appropriateness of the carers' feeding practices can be evaluated through the level of training need, which is indicated by the number of training areas initially identified. Changes in appropriateness can be measured through an increase or decrease in the number of areas identified at each assessment point as well as the scores achieved in attainment of appropriateness within each training area identified; no change (0), partial achievement (1), appropriate (2).

It should be noted that, although improvement in feeding practices is marked by a general trend of fewer aims and training areas identified, in some instances, as the skills of the children and caregivers developed, new areas of need were occasionally identified. For example, if the caregiver had moved the child from bottle-feeding to spoon-feeding, additional needs arose such as the need to provide support to the lips/jaw. At other times, additional areas were identified as a result of improvement in the child's skills. For example, the child was ready to be more involved in self-feeding.

In this section, the data derived from training areas identified and attainment sores are used not only to evaluate appropriateness of feeding behaviour and overall compliance with the training, but also to report on the areas of feeding behaviour that were most commonly identified as a training need.

3.5.1 Appropriateness of feeding practices

3.5.1.1 Aims and training areas (FORM 8)

Aims

Table 3-51 Mean number of aims identified

	BSL	PTR1	PTR2
C1&C2 (n=21)	**7.9**	**4.8**	**5.1**
SD	*2.23*	*1.92*	*1.77*

	BSL	PAR
C2A	**7.7**	**7.5**
SD	*2.41*	*1.32*

Training areas

Table 3-52 Mean number of training areas identified

	BSL	PTR1	PTR2
C1&C2 (n=20)	**17.2**	**8.2**	**8.5**
SD	*2.7*	*3.5*	*2.8*

	BSL	PAR
C2A	16.1	14.2
SD	*3.80*	*2.89*

Advice plus training

Using a one factor within-subjects analysis of variance (ANOVA), the number of aims and target areas identified were shown to reduce overall by a highly significant amount. (Aims: $F(2,36)=25.93$, $p<0.001$; Targets: $F(2,38)=111.01$, $p<0.001$). The reduction in number of aims identified was observed, using a Paired Samples *t*-Test, to be significant at PTR1 ($t(19)=4.72$, $p<0.001$) and PTR2 ($t(19)=5.79$, $p<0.001$) as was the reduction in the number of training areas at PTR1 ($t(19)=14.06$, $p<0.001$) and PTR2 ($t(19)=12.57$, $p<0.001$).

Advice only

There was no significant reduction in the number of aims identified following *advice only* ($t(19)=0.42$, $p=0.68$). Although small, the reduction in the mean number of training areas identified was statistically significant ($t(19)=2.78$, $p<0.05$).

3.5.1.2 Attainment of training targets

A total percentage score of target attainment was calculated for each caregiver using the scores they had obtained for achievement of appropriateness within each area divided by the number of targets areas identified. (Drink consistency and sensory preparation for drinks are excluded from the results as they were never set as targets). Even though the level of skill of each individual in each area was different, as was the

'learning distance' between partial or full achievement, the starting point for each caregiver was zero, as the measure was relative to each individual rather than standardised.

The table below summarises the mean percentage attainment of training targets in each cohort, at each stage of the programme.

Table 3-53 Mean percentage attainment of training targets

	BSL	PTR1	PTR2
C1&C2	**0.0**	**66.8**	**64.4**
SD	*0.00*	*12.64*	*13.02*

	BSL	PAR
C2A	**0.0**	**33.7**
SD	*0.00*	*16.10*

Advice plus training

A Friedman Test showed the results for attainment of training targets to be significant overall (Chi-Square=33.86, *df*=2, p<0.001). Behaviour change was observed, using a Wilcoxon Signed Ranks Test to be significant at PTR1 (Z=4.10, p<0.001) and sustained to PTR2 (Z=4.11, p<0.001)

It should be noted that the overall level of compliance was significantly higher in the C2 cohort (t(20)=2.82, p=0.01).

Advice only

Carers reached a compliance score of 33.7% following advice only which was shown to be significant using a Wilcoxon Signed Ranks Test (Z=3.92, p<0.001). It should be noted that the very low baseline contributed to this significant result.

It was not possible to calculate the potential impact of degree of disability, levels of income, carer education or age on overall compliance scores as the participants were too similar in these aspects.

Using Spearman's Rank Correlation Coefficient, no correlation was found between achievement of appropriate feeding and caregiver level of education or mental well-being (scored using the SRQ20 screen), however, an inverse correlation was found between child age and caregiver compliance, with caregivers of younger children achieving higher scores (*rho*=0.51, p<0.01).

In terms of level of input, the degree of behaviour change achieved following *advice plus training* was significantly higher than that achieved following *advice only* ($t(40)=6.82$, $p<0.001$).

3.5.1.3 Areas of most / least compliance

The areas of greatest achievement following *advice plus training* were responsiveness of feeding manner (amount per mouthful, pacing and delivery), utensil used and interaction style, with the majority of the scores in these areas rising to between 70% and 90%. These achievements are consistent with the significant improvements recorded in sensitivity and responsiveness, and positive and negative proactiveness, reported in section 3.4.3.

The areas of least change at PTR2 were positioning (49%), giving enough to drink (39%) and giving support to lips/jaw for food (29%). Appropriateness within these areas was rarely or never 'fully achieved' although they have particular significance in terms of safe feeding and child health. They are all interdependent and all problematic; drinking requires appropriate head positioning, which also requires adequate support to the lips/jaw. They all require a high degree of skilled physical support from the caregiver in order to be achieved.

Following *advice only*, the areas of greatest compliance (>40%) were again responsiveness of feeding manner (especially with regards to giving drinks), and utensil. Scores for caregiver interaction style were much lower. Key areas of least change were diet (33%), providing positive verbal encouragement (29%), positioning for food (28%) and providing adequate fluids (18%).

3.5.2 Comparison of statistical and clinical significance

A 50% cut-off point on target attainment scores was chosen to represent change that was clinically significant to the child. This is low, however the majority of scores exceeding 50% post training were much higher than this in reality. Scores following *advice only* did not reach higher than 56%.

The table below compares change that was statistical significance (SS) with the level of clinical significance (CS) at PAR, PTR1 and PTR2. Some of the training outcomes are reported more than once as they relate to more than one variable. Some variables were not scored for compliance, and are marked with a dash.

Table 3-54 Statistical significance versus clinical significance

	Advice plus Training				Advice only	
	PTR1		PTR2		PAR	
	SS	CS	SS	CS	SS	CS
Ensuring adequate nutrition & fluid intake						
▪ Preparation of nutritious diet ↑ *vegetables*	**Y**	***Y***	**N**	***Y***	**N**	***N***
↑ *protein*	**Y**		**N**		**N**	
▪ Feeding in response to hunger	**Y**	**-**	**N**	**-**	**N**	**-**
▪ Giving enough food	**N**	**-**	**N**	**-**	**N**	**-**
▪ Giving enough to drink	**Y**	***N***	**Y**	***N***	**N**	***N***
▪ Giving verbal encouragement	**Y**	***Y***	**Y**	***Y***	**N**	***N***
▪ Food consistency ↓*liquid* ↑*solid*	**Y**	***Y***	**Y**	***Y***	**N**	***N***
Safe & responsive feeding practices						
▪ Trunk positioning: ↓*lying/breastfeeding*	**Y**	***N***	**Y**	***N***	**Y**	***N***
↑ *45° / upright*	**Y**		**Y**		**Y**	
			N		**N**	
▪ Head positioning (Food) ↓ *extended*	**N**		**Y**		**N**	
↑ *straight / flexed*	**N**		**Y**		**Y**	
(Drink) ↓ *extended*	**Y**		**N**		**Y**	
↑ *straight / flexed*	**N**					
▪ Food consistency ↓*liquid* ↑*solid*	**Y**	***Y***	**Y**	***Y***	**N**	***N***
↑ *homogeneity*	**N**	***Y***	**N**	***Y***	**N**	***N***
▪ Appropriate utensil	**Y**	***Y***	**Y**	***Y***	**Y**	***N***
▪ Sensitivity to cues	**Y**	**-**		**-**	**N**	**-**
▪ Appropriate amount per mouthful & pacing	**Y**	***Y***	**Y**	***Y***	**N**	***N***
▪ Minimising negative interaction & forcing (V)	**Y**	***Y***	**Y**	***Y***	**N**	***N***
(P)	**Y**		**Y**		**N**	

It should be noted that although results for positioning were not clinically significant overall, this may be due to the combined score for trunk and head position. Trunk positioning alone may have achieved clinical significance in all groups.

It should also be noted that although change in diet was considered clinically significant at PTR2, it was not statistically significant. This is due to the fact that targets set were to be achievable within the social context, which meant that dietary targets were set quite low.

3.5.3 Caregiver feeding practices and child outcomes

The tables below compare caregiver behaviour change and child outcomes in the key areas of nutritional status, chest health and affect during feeding. Table 3-55 shows the outcomes following *advice plus training* (scores at PTR2 only). Table 3-56 compares caregiver behaviour change and child outcomes following *advice only*. Change in caregiver behaviour is summarised according to statistical significance (SS) and clinical significance (CS) and is compared with statistical change in the child's outcomes.

Table 3-55 Caregiver feeding practices and child outcomes: *advice plus training*

TRAINING OUTCOMES			CHILD OUTCOMES	
	SS	**CS**		**SS**
Ensuring adequate nutritional intake			**Nutritional status**	
Providing nutritious diet	**N**	***Y***	WAZ(British 1990)	***Y***
Giving enough food	**N**	**-**	BMIZ(British 1990)	***N***
Responding to hunger	**Y**	**-**	WAZ (CP 2006)	***N***
Providing verbal encouragement	**Y**	***Y***	MUAC (raw score)	***Y***
			MUACZ(CP 2006)	***N***
Safe & responsive feeding practices			**Chest health**	
Positioning	**Y** (trunk)	***Y***	Risk of aspiration (observed)	***Y***
Consistency	**Y**	***Y***	Reported frequency of chest-related illness	***Y***
Utensil	**Y**	***Y***		
Sensitivity to cues	**Y**	**-**		
Responsiveness to cues (amount per mouthful & pacing)	**Y**	***Y***		
Minimising negative interaction & forcing	**Y**	***Y***		
			Affect during feeding	
Sensitivity to cues	**Y**		Discomfort/distress during feeding (observed)	Almost
Responsiveness to cues (amount per mouthful & pacing)	**Y**	***Y***		
Minimising negative interaction & forcing	**Y**	***Y***		

Table 3-56 Caregiver feeding practices and child outcomes: *advice only*

TRAINING OUTCOMES			CHILD OUTCOMES	
	SS	**CS**		**SS**
Ensuring adequate nutritional intake			**Nutritional status**	
Providing nutritious diet	**N**	***N***	WAZ(British 1990)	***Y***
Giving enough food	**N**	**-**	BMIZ(British 1990)	***N***
Responding to hunger	**N**	**-**	WAZ (CP 2006)	***N***
Providing verbal encouragement	**N**	***N***	MUAC (raw score) MUACZ(CP 2006)	***Y*** ***N***
Safe & responsive feeding practices			**Chest health**	
Positioning (trunk; head for drinks)	**Y**	***N***	Risk of aspiration (observed)	***N***
Consistency	**N**	***N***	Reported frequency of chest-related illness	***Y***
Utensil	**Y**	***N***		
Sensitivity to cues	**N**	**-**		
Responsiveness to cues (amount per mouthful & pacing)	**N**	***N***		
Minimising negative interaction & forcing	**N**	***N***		
			Affect during feeding	
Sensitivity to cues	**N**		Discomfort/distress during feeding (observed)	***N***
Responsiveness to cues (amount per mouthful & pacing)	**N**	***N***		
Minimising negative interaction & forcing	**N**	***N***		

3.6 Caregiver feedback on the training programme

3.6.1 Specific aspects of the training

Caregivers were asked to comment on the usefulness of aspects of the training programme at their first post-training review (FORM 9). The table below summarises caregivers' responses. The numbers represent the percentage of responses in each category.

Table 3-57 Caregiver opinion on usefulness of different aspects of the training

	Not very %	Quite %	Very %
1st Home visit	27	41	27
Group training: formal teaching	4	14	82
Group training: supervised feeding	5	0	95
Video drama (*n*=19)	0	0	100
Spoon (*n*=18)	0	22	78
Cup (*n*=17)	23	12	65
Diet sheet (*n*=21)	24	1	62
Advice sheet (How to feed) (*n*=20)	15	30	55
Chair (*n*=21)	5	14	81
Overall satisfaction	0	9	91

3.6.2 General feedback

In the final training session (session 6), carers were asked for general feedback on the training programme. In terms of content, caregivers said that they found all of the advice useful and particularly appreciated being able to practice the feeding techniques with us before going home to try them. In terms of structure, several carers said that the timing was good but that the number of sessions should be increased. Carers reported having enjoyed meeting other mothers who are in similar situations and would try to stay in touch with others from their group.

Some said that they would now be able to help other mothers living nearby with similar problems. The logistics of obtaining transport to the groups was raised as problematic by two caregivers. (Payment was not an issue as all travel costs were reimbursed).

"After attending the training sessions we now know how to feed the child. I am gad that I could attend these sessions. We have learnt so many things from you an at the same time, we could share our problems with other mothers" (CHC0407)

"The things we have learnt from here we also practiced at home and in the next session we showed it in the practical part. In this way we could know what is right and what is wrong." (MUP17)

"Yes the group sessions were helpful for us. Now we use oil for cooking and we don't feed her forcefully." (Father: SR01)

"I have seen different types of children who have different problems. Not only my child has this type of problem. I liked it." (MUP17)

3.6.3 Summary

Overall, 91% of caregivers were very satisfied with the training. Supervised feeding was considered slightly more useful than the formal teaching. With regards to the materials used, 100% of the carers reported the video drama to be 'very' useful. The chair and cup were considered the most useful pieces of equipment and the pictorial advice sheet the least.

3.7 Before and after training: audiovisual illustration

3.7.1 Photographs

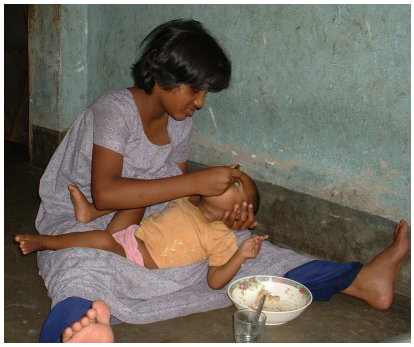
The following photographs in Figure 3.4 show children and their caregiver at their baseline assessment (Pre), and during training or at review (Post).

CDC03 Pre

CDC03 Post

CHC0408 Pre

CHC0408 Post



MUP08 Pre

MUP08 Post

CDC02 Pre

CDC02 Post

CHC0407 Pre

CHC0407 Post

OPD03 Pre

OPD03 Post

Figure 3.4 Photographs of feeding before and after training

3.7.2 Video materials

The supplementary DVD attached contains three short extracts of children in the study, taken at different stages of the programme.

Child 1 is videoed at baseline assessment, during the initial advice session and then during training.
Child 2 is videoed at baseline assessment and during training.
Child 3 is videoed at baseline and then at second post-training review.

The resultant feeding methods are not ideal, but show a marked change in practices following intervention. Child 3 was particularly difficult to seat, as she has opisthotonos (abnormal posture involving rigidity and severe arching of the back due to increased extensor tone). Achieving an ideal head position was therefore unrealistic.

In addition to the case examples is the educational video drama. The quality is not optimum as this was an amateur production and some jerking may be seen due to the formatting of the data onto the disc.

As described in Chapter 3, the video drama is a 30-minute film about a boy with cerebral palsy living in a remote village of Bangladesh, who contracts a chest infection as a result of his feeding difficulties and the mother's feeding methods. The boy is visited by a doctor who sends out a community health worker to visit the family. She teaches the parents about all of the aspects of diet and feeding that are covered in the study training group sessions and includes demonstration of the techniques taught. The parents in the film use the new methods and the child recovers from his illness. The sequence in the film is as follows:

00.00	Narrated introduction to the family and the story. The child is found sick and the father fetches the doctor.
01.50	Doctor interviews parents and examines child. Says he will send a community health worker (CHW).
06.30	CHW interviews parents and observed mother feeding the child.
09.25	CHW gives advice on feeding methods.
11.42	CHW demonstrates and supervises mother.
17.47	Narrated summary of what the CHW has taught, accompanied by photographs.
21.36	CHW gives detailed dietary advice.
25.38	Doctor returns. Examines the child and congratulates the parents in the child being well again.
27.30	Final narrated summary of what has been taught, accompanied by photographs.

Chapter 4

Discussion

4 Discussion

This chapter is divided into four sections. The first of these discusses the participants in the study, comparing them with the local population and similar populations described in the literature. This includes the socio-economic status of the families, the children's nutritional status, health status, feeding skills and stress of mealtimes and the caregivers' psychological well-being, stress of mealtimes and feeding practices. The use of available local services is also discussed.

The second section discusses the key outcomes of this study in relation to the children and the potential impact of these changes on caregivers, associations and correlations between changes in caregiver feeding practices and child outcomes and finally, potential influencing factors on compliance.

The third section discusses the overall barriers to and favourable indicators for caregiver change and the fourth section examines the strengths and limitations of the study.

4.1 The Participants

In this section a comparison is made of the study population with the general population in Dhaka and with other children with feeding difficulties and their caregivers in similar studies, to enable a more informed interpretation of the results. For this, key themes reported in the literature have been selected.

4.1.1 The socio-economic environment

Data available on the socio-economic environments of the participants in the current study are compared with data collected on urban Bangladeshi households, taken from a total sample of 3069 households (rural and urban) interviewed as part of the Bangladesh government's Child and Mother Nutrition Survey (CMNS) (2005). The data are summarised in the table below.

Table 4-1 Participants: socioeconomic data

	Current study	CMNS (2005)
Number of people per household	Mean number of persons 5.53 (*SD*= 2.43). 63.9% 3-5 persons.	72.3% 5-7 persons
Mean monthly household income (Taka)	Tk 5173.1 (*SD*=3833.97) (*n*=4 >10,000)	Tk 9687.00
Access to flush/sanitary/water seal toilet	78.4%	37.3%
Mother's education	55.6% Primary completed	21.8% Primary completed

The households in the current study were on average smaller than those in the 2005 survey. The study families had few children and rarely had a child younger than the one with disabilities. This may be due to the fact that they were mostly young families. It may also be that they felt unable to have more children whilst they were so busy caring for their disabled child. Access to sanitary toilets was high amongst the study population (78.4%), and approximately double that of the survey families. Twice as many study mothers had completed primary education. These factors suggest that the study families lived in relatively well-serviced slum areas. However, the average income of the study families was almost half that of the surveyed families. This supports the link between poverty and disability explained in Chapter 1 (p.21) where families who have a child with disabilities are worse off due to extra costs and fewer opportunities for employment.

It is worth noting (see Results chapter, p.98) that where participants lived in joint family households, 43% of these were with the mother's family. It is most common in Bangladesh to live with the husband's family, however, many of the carers in the study reported rejection from the husband's family due to having a disabled child. This may have contributed to the high numbers therefore living with the mother's side.

4.1.2 The children

4.1.2.1 Nutritional status

As outlined in the Methods chapter, nutritional status was assessed in this study through anthropometry, the results of which are used in this section to compare the study children with their non-disabled peers (see table 4-2) as well as children with disabilities from other studies, and their sibling or neighbour controls[8] (see table 4-3). For the purposes of comparison, growth references and age ranges were selected which matched those used in the comparative studies. Nutritional status is also compared with that of children with moderate-severe CP in the USA (see table 4-4) by

[8] Sibling or neighbour controls in table Y denoted in blue italics.

calculating *z*-scores using the CP growth charts (Stevenson *et al*., 2006). (It was not possible to calculate measures involving height using these standards).

Table 4-2 Current study children: nutritional status compared with Bangladeshi controls

	Current study children BANGLADESH 1-5 years (*n*=29) (WHO[9])		Child and Mother Nutrition Survey, 2005 BANGLADESH[10] 1-5 years (*n* =not known) (WHO)	
	Mean	*SD*	Mean	*SD*
MUAC (cm)	14.7	*1.55*	14.6	*1.30*
MUACZ	-0.89	*1.24*		
WAZ	-3.47	*1.25*	-1.40	*1.21*
HAZ	-2.46	*1.47*	-1.49	*1.52*
WHZ	-3.07	*1.44*	-0.80	*1.29*

Table 4-3 Current study children: nutritional status compared with disabled children from other studies

	Current study Children BANGLA-DESH CP (*n*=37) 1-11 years (Severe 33; moderate 4) (NCHS, 1979[11])		Krick *et al*. (1996) USA Quadriplegic CP (*n* =360) 0-10 years. (NCHS, 1979)		Socrates *et al.* (1997) PHILIPPINES CP (*n*=31) 2-10 years. (Severe 14; moderate 12; mild 5) (NCHS, 1979)		Thompsett *et al.* (1999) NIGERIA CP (*n*=23, out of total *n*=311). 0-10 years. (Severe CP or feeding difficulties excluded). (NCHS, 1979)		Yousafzai *et al.* (2003) INDIA Range of disabilities (*n*=141) 2-6 years. (NCHS, 1979)	
	Mean	*SD*	Mean	SD	Mean	*SD*	Mean	*SD*	Mean	*SD*
MUAC (cm)	14.7	*1.55*					15.2	*1.5*	14.6	*18.0*
							15.7	*1.40*	*15.10*	*15.00*
WAZ	-3.50	*1.00*	-2.4 (m) -2.1 (f)		-3.39	*1.03*	-2.0	*1.2*	–2.44	*1.39*
					-1.68	*0.98*	*-1.00*	*1.20*	*-1.70*	*1.20*
HAZ	-2.71	*1.90*	-2.3 (m) -2.1 (f)		-3.10	*1.25*	-3.0	*1.6*	-2.67	*1.92*
					-1.51	*1.39*	*-1.50*	*1.70*	*-1.82*	*1.87*
WHZ	-2.72	*1.24*	-1.3 (m) -1.1 (f)		-2.56	*1.33*	-0.4	*1.1*	-1.27	*1.14*
					-0.93	*0.75*	*-0.20*	*2.10*	*-0.95*	*0.97*

[9] World Health Organisation Growth standards, 2006.
[10] Non-disabled urban under-fives taken from the Bangladesh Child and Mother Nutrition Survey (CMNS) 2005
(Bangladesh Bureau of Statistics, 2005)
[11] National Center for Health Statistics (NCHS) references (Hamill *et al.,* 1979)

Table 4-4 Current study children: nutritional status calculated using CP growth charts

	Current study children, calculated using Stevenson *et al*. (2006) growth charts (USA) 2-19 years (*n*=31)	
	Mean	*SD*
MUACZ	-0.63	*0.77*
WAZ	-2.60	*1.70*

Using the WHO growth standards (2006) the children in the current study (<5 years of age) were 2.1 z-scores below their non-disabled controls with regards to mean values for weight-for-age (WAZ), 0.97 *z*-scores below for height-for-age (HAZ) and 2.27 *z*-scores below in weight-for-height (WHZ). Mean values for MUAC were similar however. These figures suggest the study children were smaller than their non-disabled peers.

The differences in nutritional status of the children in this study and the children with cerebral palsy in the other studies may be explained in part by the differences of severity of physical impairment. The study by Thompsett *et al.* (1999) actively excluded children with severe impairments and the one by Yousafzai *et al.* (2003) included children of a greater range of disabilities (both in terms of type and severity), leading to lower levels of malnutrition in these study populations. The difference in level of nutritional status compared with the children in the Krick study may be accounted for by the fact that initial birth weight is likely to have been higher for these American children born of mothers of a higher nutritional status themselves, and also because nutritional therapy would have been available to many of these children as their deficits became apparent. In their study, 50% of the children with the most severe difficulties were being tube-fed. The nutritional status of the children in the current study is most similar to that of the CP children assessed in the Philippines, who are descriptively more similar also. These children are on average 1.5 *z*-scores below their controls. With regards to the children in the current study however, they were at least 2 *z*-scores below their comparative group on measures of wasting (WA and WH) even though the nutritional status of the control population is similar to that in the Philippines, suggesting that the children in the current study were even more malnourished.

As growth patterns in children with CP are different from those in the general population (Krick *et al*., 1996; Kuperminc and Stevenson, 2008), the degree of malnutrition within the study population cannot be judged directly from the scores achieved using the growth references developed for non-disabled populations. Recent growth references developed specifically for CP children over 2 years of age and with

moderate-severe CP (Stevenson *et al*., 2006), revealed the current study children of this age group to be 2.6 *z*-scores below their American counterparts in WA but only 0.63 below in MUAC. The difference in deficit between the WAZ and MUACZ scores suggests that the current study children were smaller rather than thinner than their reference group in the USA. (It was not possible to calculate *z*-scores involving height measures with the available data to corroborate this). Again, this is likely to be, in part, due to widespread malnourishment amongst the general population in Bangladesh, leading to lower birth weight and general stunting in addition to the lack of availability of nutritional therapy for the CP population.

It should be noted that although issues regarding fluid intake amongst the CP population are not discussed widely in the literature, this was of particular concern for the children in this study, three of whom were admitted to hospital suffering from dehydration during the study period.

4.1.2.2 Health: respiratory and general

The respiratory health of the study children was overall more severely affected than reports of children with CP in studies conducted in well-resourced countries. As summarised in the table below, 31% (*n*=271) of the children the in Oxford Feeding Study (Sullivan *et al*., 2000), 93% of whom had cerebral palsy were reported to have suffered one or more chest infections in the previous six months. This is in contrast to 62% of the current study children who were reported to have chest-related illnesses at least once every three months. 56% of the Oxford parents reported their child choking on food and 38% of the 49 children with CP in the Reilly *et al.* population survey (1996) were reported to have swallowing problems. However, 88% of the current study caregivers reported coughing during feeding, 35% of whom said it occurred all/most of the time. As reported earlier, (see Results chapter, p.96), signs indicating a risk of aspiration during feeding (*pharyngeal signs*) were observed in 97% of the current study children at the first assessed mealtime, occurring frequently in 65% of those.

Table 4-5 Respiratory and swallowing status: comparison with other studies

	Current study	Sullivan *et al.* (2000)	Reilly *et al.* (1996)
Chest infection/chest-related illness	62%: 1+ every 3 months	31%: 1+ in previous 6 months	
Swallowing problems	88% cough on food 97% observed at risk of aspiration	56% choked on food	38% swallowing problems

Sullivan and colleagues found that those children who choked on liquids also had problems swallowing lumpy foods, took longer to feed, had more difficulties feeding

themselves and were less interested in food. This finding is mirrored in the current study by the consistent high percentage of children who presented with difficulties in all of these areas mentioned.

Reasons for the frequency of chest-related illnesses in the study population may in part be explained by the general ill-health of the wider population, who also suffer frequent chest-related illnesses, respiratory illness being one of the commonest causes of death in children living in Dhaka slums (Podymow *et al*., 2007). Another factor is the consistent severity of CP in the study population (higher than in the aforementioned studies by Sullivan *et al.*, 2000 and Reilly *et al.*, 1996).

In terms of general health, 39% of the study children had been sick in the two weeks prior to the first interview (see Results chapter p.96). Liptak *et al.* (2001) also found that children at GMFCS level V and with severe feeding difficulties, living in a well-resourced country, required the most health care resources, used the most medications, had the most respiratory problems and had the lowest Global Health scores of all of their study population. Morbidity is high in the Bangladeshi population, especially amongst those suffering from severe malnutrition. In the study by Khanum *et al.* (1998), of 437 Bangladeshi children who had been treated for severe malnutrition in the previous year, follow-up revealed a mean of seven episodes of diarrhoea and 58% of cases of pneumonia (10% had pneumonia three times). This level of morbidity is not necessarily reflected in the general population, as suggested in the report by Podymow *et al*. (2007), in which 76% of children in the Dhaka slums (*N*=100) were reported by their parents to have good or very good health.

4.1.2.3 Feeding skills & time for feeding

Overall, the study children presented with extremely poor feeding skills, similar to those of the most severely affected children in other studies.

The children in the current study were all severely delayed in oromotor skills for feeding, with only one child showing any signs of chewing, a skill which usually starts emerging at around 8-10 months of age (Bronner *et al*., 1999). As reported above (Results chapter p.100), marked oral spillage was said to occur in 81% of the children and observed in 76%. This is comparable with the children in Reilly *et al.*'s study (1996), of whom 90% had clinically significant oromotor dysfunction, but possibly more severe than those in the Oxford study (Sullivan *et al.,* 2000) where drooling during feeding was reported to occur most of the time in 28% of the children.

Observations of mealtimes in the current study revealed average meal lengths of under 30 minutes although caregiver estimates were considerably higher than this. Considering the severity of the oromotor difficulties experienced by the study children, this suggests a high risk of undernutrition, as much greater amounts of time would be required in order to achieve adequate nutritional intake (Johnson and Deitz, 1985; Reilly, 2001).

None of the children in the current study were involved in self-feeding to any degree at first assessment. In the Oxford study (Sullivan *et al*., 2000), where there was a range of severity of impairment, 89% needed help with self-feeding. Yousafzai *et al.* (2003) reported only 39% requiring help, however, in her study only 28% had severe feeding difficulties.

4.1.2.4 Stress of meal times

As outlined above (see Results Chapter p.96) mealtimes in the current study were an uncomfortable experience for the majority, with 65% of the children reported by carers to be distressed some or all of the time during feeding. 84% of the children were reported to refuse their food (some or all of the time) and 70% were reported to be fussy eaters, which may be indicators of stress. 57% of cases during the first assessed mealtime were observed by the researchers to involve discomfort or distress. In the Oxford study (Sullivan *et al*., 2000), correlations were found between perceived child stress at mealtimes and severity of motor impairment, drooling, problems managing 'lumpy' food, prolonged feeding times, and chest infections. Those with poorer health and nutrition were also perceived to be more stressed. These features were present in the majority of our study children and were likely contributors to their stress during feeding.

4.1.3 The caregivers

4.1.3.1 Psychological well-being

In this study, caregivers gave a mean score of 10.39 (*SD* 4.4) on the SRQ20 (Harding *et al*., 1980) with 74.2% scoring above 7 (the cut-off for psychological disturbance). Mean levels of anxiety identified by Mobarak *et al.* (2000) using the same tool amongst a group of Bangladeshi mothers of children with disabilities living in urban areas (not necessarily with feeding difficulties) were only 5.14 (*SD* 3.64). Reilly and Skuse (1992) however, identified that 83% of 12 case mothers of children with cerebral palsy and feeding difficulties scored above the threshold for clinically significant psychological disturbance using the General Health Questionnaire (28-item version; Goldberg and

Hillier, 1979 cited in Reilly and Skuse, 1992). When comparing these studies, it is the carers whose children have feeding difficulties who are most anxious.

Maternal depressive symptoms have been linked to greater emotional distress, a higher perception of interference with daily activities caused by the child's condition and less confidence in managing the child's problem (Bartlett *et al*., 2004). The majority of the caregivers in the current study certainly reported their children's feeding problems to be highly stressful, that they disrupted their daily routine, even when support was available, and that they felt a lack of confidence in how to feed their child.

Interestingly, caregivers in the study with children who were classified at level III (GMFCS) scored consistently below 7 on the SRQ20 screen. Mobarak *et al*. (2000) found no relationship between these two. In their study, levels of caregiver stress were correlated with the child being older or having behavioural difficulties. As only three of the children in the current study were functioning at level III (GMFCS) the numbers are too small to be conclusive, however, the feeding difficulties of those three were less marked and therefore may have accounted for the lower stress levels in these carers.

4.1.3.2 Stress of mealtimes

As previously outlined (Results chapter, p.103), 89% of the caregivers in this study, when first interviewed (*N*=37), reported feeling *very* stressed about their child's feeding problems. 91% of C1 and C2 (*n*=22) carers said that mealtimes were a negative experience for them, and reported a total of 50 negative feelings between them when asked how they felt during feeding itself. Only two carers said that mealtimes were 'all right' because they were used to them. In the study by Reilly and Skuse (1992), 8 out of 12 mothers said that mealtimes were not an enjoyable experience. In the Oxford study (Sullivan *et al*., 2000) only 20% of the caregivers described mealtimes as stressful.

Key themes that arose when caregivers in the current study were asked what bothered them about their child's feeding difficulties, were the fact that their child did not eat like other children, concern about the nutrition and health consequences of their child being able to eat only a limited diet, the fact that the child could not feed itself and so may go hungry (because the caregiver was busy and was not always able to feed the child), the time-burden, the physical effort involved in feeding their child, the financial burden and feeling unskilled. Carers also reported a mixture of feelings in relation to themselves and their child, which included sadness, upset, fear, guilt, a sense of burden and despair.

Similarly, themes arising in the study by Reilly and Skuse (1992) included carers being worried that their children were not eating enough, having 'great difficulty' with feeding their child and only 1 out of the 12 felt confident that she was giving her child the right food. Insufficient time was a theme that arose in caregiver interviews in the Dharavi study (Yousafzai *et al.*, 2003a), reported by 62% of those whose children were unable to self-feed. Although the numbers of caregivers reporting stress regarding feeding in the Oxford study (Sullivan *et al*., 2000) are not as high, the reasons given were similar to those given by the caregivers in the current study. These included concern that the child was underweight, stress where the child needed a lot of help with feeding and stress due to the extra time burden, the need for extra food preparation and extra costs associated with feeding. Stress was also associated with the severity of the child's motor deficit, and specific feeding difficulties such as drooling, choking with solids or liquids. Likewise, caregivers in the current study were bothered that their child could not sit to eat and were annoyed by oral spillage, regurgitation and the child not being able to chew.

As previously described (Results chapter p.103), 90% of the carers in this study said that mealtimes took a long time (60% said 'always' and 30% said 'sometimes'), and 76% at initial assessment were reportedly spending between 2.5 and 5 hours a day feeding their disabled child. Although this does not match the researcher observations in this study, it is comparable with caregiver reports from other studies. Carers in the study by Johnson and Deitz (1985) reported an average time to feed children with CP and feeding difficulties of 3.5 hours per day compared with 0.8 hours for non-disabled children. Some of their caregivers were spending up 7.5 hours a day in feeding. In the study by Sullivan *et al.* (2000), 51% of the children with severe disabilities were spending more than 3 hours per day in feeding. 67% of the Indian caregivers in the study by Yousafzai *et al.* (2003) reported that feeding their disabled child took longer than feeding their siblings, however 18% reported feeding to take less time. Reilly *et al.* (1996) also noted the extreme brevity of some mealtimes in their study observations, which ranged from 5 minutes to 41 minutes, brevity usually being associated with difficulty. In the current study, 78.4% of caregivers initially reported meals taking longer than 30 minutes, 67% said they were sometimes short of time for feeding, and time limitations were later reported as one of the main barriers to compliance. In observations of the initial C1 and C2 mealtimes however, not one typical mealtime exceeded 15 minutes. The shortest was 3 minutes.

Caregiver perception of mealtime length can in itself be a reflection of difficulty with feeding and caregiver stress (Reilly *et al.* (1996) which may account for the discrepancy between observed mealtime length versus caregiver reports in the current study. The findings mirror those of the study by Reilly *et al.* (1996) (see Chapter 1, p.42), in which carers were found to overestimate mealtime length, with the discrepancy between caregiver perception and observations increasing with the severity of the child's oromotor deficits. In the current study, the majority of the children had severe oromotor difficulties which might explain the substantial difference between observations and perceptions.

It may be argued that initial mealtime observations in this study may have been unrepresentative of usual mealtimes and shorter in this respect, as suggested by the increase in mean length of meals at PAR (see Results chapter, p.129), unaccounted for by any change in caregiver feeding practices. The caregivers and children may have behaved differently at first assessment due to the presence of the researchers and camera, even though carers later reported not having felt uncomfortable or having behaved differently in spite of this. Nonetheless, despite any potential underestimation at baseline, the size of the discrepancy between researcher observations and caregiver reports suggests that carers were still likely to have been overestimating mealtime length.

4.1.3.3 Feeding practices

(i) Specific aspects

Food given

The food intake of the children in the current study was similar to that described in studies carried out in other parts of the world. As reported above (Results Chapter, p.106), the children ate, on average, five times a day including main meals and snacks. They were reported to eat less than their age-equivalent siblings due to the lack of ability to forage for food and 49% of children were reported not to be fed when they were hungry but rather when their caregivers had time. The diet was predominantly milk or carbohydrate-based and therefore lacking in variety and nutritional value. In the study by Reilly & Skuse (1992), the children ate three meals per day plus an occasional snack or drink. The children were offered and consumed less than their comparison group and the diet was restricted in taste, texture and variety (10 out of the 12 children were given powdered baby foods as these could easily be diluted to an easy texture to manage). In the study by Sullivan *et al.* (2002), the children with severe disabilities gained the highest proportion of their energy and micronutrients from milk and milk-based drinks, as these were the easiest 'foods' to eat. For 80% of their cohort, the diet

was deficient in energy (compared to that consumed by non-disabled peers) and lacking in micronutrients. It would appear then that global locality does not have much influence on the diet of these children, which is in fact dictated by their physical limitations and caregiver struggle to find appropriate and manageable foods for them to eat.

Positioning and seating equipment

As described in the Results chapter (p.107), at the first mealtime observation, children in the study were more than twice as likely to be fed in lying or breastfeeding position, than semi-reclined or upright. Head positioning was observed in extension in 100% of cases at some point during the assessment. Positioning was identified as a training target for 100% of caregivers at first baseline. In contrast, only 15% of the caregivers in the Indian study (Yousafzai *et al*., 2003a) showed needs in this area, undoubtedly because more of these children were able to sit independently. Interestingly, in the study by Reilly and Skuse (1992), which took place in an environment where high technology assistive equipment was available to caregivers, they were still using a variety of positions for feeding, the majority of which were considered to be inadequate and included feeding in semi-reclined position or lying on the sofa. Only 33% were considered to be seated 'well' by an independent physiotherapist.

Verbal interaction and feeding manner

As reported above, (see Results chapter, p.104), positive verbal encouragement was used by the caregivers in this study either *never* or *occasionally* in 84% of initial observed mealtimes. Negative verbal interactions were recorded in 80% of cases and negative physical behaviour in 87%. Lack of responsiveness was observed in 89% of caregivers. Reilly & Skuse (1992) also comment on the 'striking' lack of verbal interaction during feeding (in contrast to outside mealtimes) observed in their study group, and the fact that children were fed in a very 'mechanical' way. Rather than lack of verbal interaction and controlling feeding behaviours being culturally driven, as might have been the case in this study group, it would appear that the causes are more universal to the feeding situation involving a child with severe disabilities. Instead, lack of verbal interaction may reflect the limited communication skills of the children themselves, as, according to Moore *et al*. (2005) mothers are seen to use more active verbal encouragement during feeding when their children themselves were more active communicators. Likewise, the more rigid and controlling feeding methods may be a reflection of lack of caregiver sensitivity and misinterpretation of their child's behaviours. As mentioned in Chapter 1, this may be due to the caregiver's lack of

mental well-being (Hurley *et al*., 2008) as well as due to the difficulty in reading their disabled children's cues (Reilly and Skuse, 1992).

(ii) Possible influencing factors

Impact of psychological well-being

The literature suggests a correlation between mental well-being and responsiveness of feeding method (Coulthard and Harris, 2003; Hurley *et al*., 2008). In the current study however, there was no correlation observed between scores for psychological well-being and overall level of training need or responsiveness of feeding manner (i.e. speed and mouthful size).

Impact of education

Guldan *et al*. (1993) saw distinct differences in the feeding practices of Bangladeshi mothers of differing levels of education. Amongst other differences, caregivers in families with education fed their children more frequently, were more attentive, used utensils more frequently, and introduced weaning foods sooner. Nahikian-Nelms (1997) also found positive correlations between nutrition knowledge, attitudes and subsequent caregiver behaviour at mealtimes. The results from the current study match with this, whereby lower levels of caregiver education were correlated with a higher number of training needs identified at baseline.

4.1.3.4 Contact with services

Lack of contact with services is again a global issue. 35% of the all the caregivers questioned in this study reported having had no previous contact with disability services or contact on one occasion only. In the study by Reilly and Skuse (1992), 5 out of the 12 mothers (42%) had received only minimal assistance in managing their child's feeding problems. Only 3 mothers were currently receiving advice, 2 mothers were unaware that help was available and only 2 had received advice on nutrition. Sullivan *et al*. (2000) discovered that 64% of their respondents' children had never been assessed specifically for feeding or nutritional problems and 53% had not been seen by any healthcare professional within the previous 12 months. Reasons for lack of contact with services appear to range from lack of availability to lack of awareness and knowledge of what services exist and what services to seek.

4.1.4 Summary

The caregivers and children in this study exemplify the consequences of caring for and being a child with severe disabilities and feeding difficulties, as described in Chapter 1. The majority of carers scored above the threshold for psychological disturbance on the stress measure (SRQ20), and reported very high levels of concern and stress regarding their child's feeding. The children were largely underfed and under-watered, fed in an unsafe, insensitive, unresponsive and disrespectful manner, suffered frequent chest-related and general illnesses and both caregivers and children were marginalised, with limited support and access to services. Carers said that their disabled children ate less often than their peers because they could not feed themselves and the carers did not always have time to feed them. Children were not fed often enough or to satiety because their carers did not know when their children were hungry or full, because they lacked time or because they got fed-up. Mealtimes were so difficult that sometimes caregivers refused to feed the child. Verbal and physical abuse was frequently reported.

4.2 Discussion of outcomes

4.2.1 CHILD outcomes

4.2.1.1 Impact of child development

It should be recognised that progress in areas related to child development (i.e. growth, oral feeding skills and self-feeding) could have been expected during the study period, independent of any intervention. It is therefore important to compare any change observed with the change that might be expected in these specific areas over the same period of time within the population of children with moderate-severe CP. Standardised comparisons only exist for growth measures, which are discussed below. With regards to oral feeding skills, the pace of change in terms of maturity of oral feeding manner within the study population was faster than that expected of normally developing children who take an average of six months to move between each oral stage (Arvedson and Brodsky, 2002). The study children were very delayed in their oral skills at baseline and proceeded to move quickly between stages towards chewing. This suggests some catch-up of skills taking place, facilitated by caregiver behaviour, through the change of positioning for feeding and the food consistency rather than due to the process of child development. The reduction in oral spillage was also likely to be more related to changes in caregiver feeding practices, especially those of speed of delivery and quantity per mouthful, for which caregiver compliance was high, rather than change in child skills. The same is likely with regards to improvements in self-feeding where significant changes, observed largely in children who were less disabled, had occurred already by the post-advice review, suggesting that carers were over-supporting these children and that the improvements were a result of changes in caregiver feeding methods.

4.2.1.2 Effectiveness of the intervention

This section will discuss the effectiveness of the intervention in terms of impact on child nutritional status and health (especially respiratory).

(i) Nutritional status

As summarized in the Results chapter (p.112), significant increases in WAZ were observed overall following *advice plus training*, when using the British 1990 growth references (Cole *et al.*, 1998). The degree of change was not statistically significant using the CP growth charts (Stevenson *et al*., 2006), even when comparing the outcomes with those for children of the same age range. The reason for the lack of significant change observed using the CP growth standards may be due to the

children's values being closer to the norm when using these references, necessitating greater change therefore, in order to show a significant difference. Differences in outcome using the two reference standards may also be due to differences in their sensitivity and specificity.

It may be more appropriate to analyse the results in terms of clinical significance however. Based on an increase or decrease of -0.5 *z*-scores demonstrating a change of clinical significance (adapted from the guidelines of Ong *et al*., 2000; see Results chapter, p.106) 6% of the study population showed clinically significant increases in WAZ using the British 1990 growth standards (Cole *et al*., 1998) and 22%, using the CP growth charts (Stevenson *et al*., 2006). Losses of the same number were observed however, using the British 1990 references (designed for non-disabled children) but only 0.06% of the children (>2 years of age) showed a clinically significant decrease using the CP charts which, as they are based on data gained specifically from the CP population, are likely to present a more valid representation of the outcomes. Following *advice only*, 35% and 13% showed clinically significant increases in WAZ using the British 1990 and CP growth charts respectively. There were no clinical decreases.

The fact that growth trajectories were maintained or improved (even to a small degree) in the majority of cases was a positive outcome, as this alone is recognized to be a huge challenge within this population (Gisel *et al*., 2003). It should be noted however, that at PTR2, the mean WAZ of the C1 and C2 children remained 4.07 *z*-scores below the international standard for non-disabled children and 2.32 *z*-scores below the international standard for children with moderate-severe CP, reflecting a severe degree of malnutrition.

MUAC raw scores increased significantly both after *advice plus training* and *advice only*, however, MUACZ(CP 2006) scores did not change significantly at either assessment point. The difference in outcomes using raw scores and *z*-scores is partly due to the fact that *z*-scores correct for age. The outcomes for these suggest that the increase in MUAC scores may have been due to developmental growth alone and not due any catch-up growth or may in part be due to the fact that these values were already close to the norm at baseline and therefore proportionally greater gains would have been necessary for significance to have been achieved.

The unexpected outcomes for growth in the C2A children at their post-advice review may, in part, be due to the fact that this took place during the harvest period, combined with the high responsiveness of feeding manner, observed in this group. The impact of

season on food consumption and growth is recognised in Bangladesh. In a study by Brown *et al*. (1985), the average energy consumption for 70 children (5-30 months) from two villages in Bangladesh was approx 33% greater during the post-harvest periods than during the pre-harvest monsoon period due to the distinct seasonal patterns of consumption of rice and wheat, the major non-breast milk sources of energy and protein. Likewise, Fauveau et al. (1992) suggest that seasonal and epidemiological factors impacted on the variability of effectiveness of their food supplementation programme in urban Bangladesh across different times of the year.

As can be seen from the data (Results chapter, pp.113-114) there was a large disparity in growth patterns of the current study population. Growth in individuals may have been impacted upon by external influences, the main ones being food availability, calorie density of the diet (e.g. extra oil) and child health. However, when examining these factors in relation to the children who gained or lost weight, no clear patterns of association emerge. Nonetheless, what does emerge is that the overall pattern of growth of the study population matches that described in the literature. The mean WAZ score of the group of children over 2 years of age was -5.33 (*SD* 1.53) at baseline, compared with -2.69 (*SD* 2.01) for those under 2 years (British 1990 growth references). This observation is commensurate with the theory that growth in these children slows down with increasing age (Stevenson *et al*., 1994).

The gains in growth in this study were modest in comparison with gains made in the Bangladesh nutrition study with non-disabled children, who gained significantly in weight, without food supplementation, even after 3 months (Roy *et al*., 2005), where weight gain was largely attributed to more frequent meals. In studies with disabled populations, catch-up growth has been observed through oral means alone (Evers *et al.,* 1991) however this was achieved through increased calorie intake rather than individuals' ability to eat more food. In the study by Gisel *et al*. (2003) with children with cerebral palsy, sufficient weight was gained only to maintain their growth trajectories and catch-up growth was not achieved through oral means alone. In spite of non-nutritional reasons for slower growth rates in this population (Stevenson *et al*., 1994), exacerbated by the severe degree of underweight of the study group which slows growth rates further (Samsung-Fang and Stevenson, 1998), the main reason for the modest gains in this study and others, is most likely due to the children being physically unable to take in more food. Evers *et al.* (1991) were unsuccessful in introducing additional snacks between meals due to the time it would have taken to eat them. According to Gisel and Patrick (1988), in order to compensate for the potential detrimental effect of this oromotor dysfunction on nutritional intake, daily feeding times

would need to be longer than normal waking hours. The calorific content of the food therefore needs to be much higher in order to compensate and may not have been sufficiently high in many cases in the current study.

A further limiting factor to growth may be the fact that the study children were introduced late to 'lumpy solids', which contain a higher density of calories than more pureed food. Northstone *et al*. (2001) observed that non-disabled infants who were introduced to lumpy solids at an earlier age (6-9 months) consumed a greater variety of family foods at the age of 15 months and that those who were introduced late to lumps (10 months or older) were more difficult to feed and had more definite likes and dislikes. One of the barriers to compliance reported by caregivers was their child's resistance to change. None of the study children were introduced to lumpy solids before 10 months of age.

Season itself did not appear to impact on the outcomes of those who attended the training groups. Brown *et al*. (1982) found that growth measures in Bangladesh were generally lowest post monsoon season until the harvest (August to December), with wasting being especially affected. In contrast, measures taken in January and February were at reference level. However, in the current study, scores of growth were higher for C2 than C1 despite the fact that the second post-training review for the C1 cohort took place between December and February (the high growth season) and review of the C2 cohort took place at the end of the monsoon season (the low growth season).

Food availability outside seasonal influences may have had an impact on the outcomes of the study. Caregiver reports (which did not coincide with seasonal patterns) suggest that food availability became an increasing issue for all the groups, affecting food quality rather than quantity. This implies that changes in diet may have been more marked if food had been more available. Food availability was reported as an issue at PTR2 by 40% of C1 caregivers in contrast with only 25% of C2 carers. Compliance on dietary change was lower amongst the C1 carers at PTR2.

The impact of illness on nutritional status is also recognised in Bangladesh, and again, this is subject to seasonal variation. Brown *et al*. (1985) saw a 10% decrease in overall food intake during illnesses involving fever. Rousham and Mascie-Taylor (1995), who conducted a study on non-disabled 2-6 year olds in Bangladesh, found that the greatest deterioration in short term nutritional status was associated with episodes of fever, followed by episodes of diarrhoea and respiratory infections. However, they found the relationship between the two varied across seasons, with significantly greater

weight loss and decreases in MUAC associated with infection in the dry and monsoon season as opposed to during the winter months. Again, our results do not mirror this picture. Individual caregivers did report a decrease in intake and a change to more milky foods during such illnesses, however, the anthropometric results do not match with these seasonal changes in health. Furthermore, as the overall health of the children improved, the potential impact of illness would have reduced over time.

(ii) Reduction in respiratory illnesses and general morbidity

As outlined by Gisel *et al*. (2003), an association between respiratory complications and aspiration has been recognised for many years, as has aspiration with swallowing difficulties (Loughlin and Lefton-Grief, 1994) and GOR (Gisel *et al*., 2003). Improvements in positioning (Gisel *et al*., 2003; Larnert and Ekberg, 1995) and food consistency (Rogers *et al.*, 1994; Gisel *et al*., 2003) have also been seen to have a positive impact on risk of aspiration.

In the current study, significant reductions in the frequency of chest-related illnesses were observed, accompanied by significant improvements in appropriateness of the food consistency and trunk positioning for feeding, both in those whose caregivers had undergone *advice plus training* as well as those who had received *advice only*. Medication for GOR was minimal and inconsistent across all groups. Observed signs of aspiration also reduced significantly in those who had received *advice plus training*, however, this was not evident in the group who had received *advice only* (C2A). It is possible therefore that the reduction in chest-related illnesses in the C2A cohort may partially be accounted for by the season in which they were assessed. C2A children were initially assessed during the monsoon period, which is known to be associated with the highest prevalence of fever, respiratory infection and diarrhoeal diseases (Rousham and Mascie-Taylor, 1995). Their second assessment (PAR) took place during the post-monsoon/harvest period when individuals are known to be healthier. Likewise seasonal variation in morbidity may have impacted negatively on the results for respiratory health in the C1 children at PTR1 and positively at PTR2. However, gains made in the C2 cohort were sustained at PTR2, in spite of the potential adverse affects of the season. In this instance, it may be that reductions in aspiration superseded the potential negative impacts of the season.

Child health has an enormous impact not only on the child's own development and ability to participate in positive activities, but also on the rest of the family. A sick child is an extra burden on the caregiver's time, leaving less time available for the rest of the family. It is also a drain on the family's finances due to money needed for doctors' fees

and medicines and the inability of the main caregiver to earn money whilst caring for the sick child. Improvements in this area therefore have far-reaching effects and are fundamental to the well-being of all concerned.

4.2.2 Associations between outcomes for children and caregivers

The most common overall concerns reported by caregivers were that their child could not eat like other children and that they feared for their child's nutrition and health as a consequence of not being able to eat and drink properly. Significant improvements were reported in the children's health and nutritional intake and concerns in these areas likewise reduced markedly, although levels of the latter were still seriously inadequate in the majority of cases.

With regards to eating like other children, although training led to significant changes in the degree of 'normalisation' of the children's feeding manner (in their ability to manage more solid food, sit more upright for feeding and use more age-appropriate utensils), the majority were still totally dependent on their carers for being fed, and continued to have significant oromotor feeding difficulties. At the first post-training reviews, caregivers identified more difficulties than at baseline assessment, which demonstrates a heightened awareness and knowledge of the issues. However, the comments during the second reviews were markedly different and carers often said their child did not have difficulties anymore, although it was clear to the researchers that this was not the case. It is felt that this mismatch is probably a reflection of the marked decrease in stress and increase in acceptance in relation to these problems, which in turn was impacting on their perception of the level of difficulty. This is suggested by some of the caregiver comments. One caregiver reported, *"Before, I felt annoyed and angry during mealtimes but now I feel that if I feed my child in the new way, slowly he will improve. I don't feel annoyed or angry anymore."* (CDC02, PTR1). *"Now I know this is the reality it doesn't bother me."* (CHC0402, PTR2). It appears that the experience of the training allowed carers, over time, to come to some internal resolution with regards to their children's feeding difficulties.

The two most common reasons reported by caregivers themselves for stress during mealtimes were that feeding took a long time and that the children did not want to eat. Caregiver reports of mealtime length and food refusal were both markedly reduced following training and concerns in both had likewise reduced. Considering that perception of mealtime length may be influenced by caregiver stress (Reilly and Skuse, 1992), the reduction in the reported length of mealtimes in the current study may reflect the fact that mealtimes became less stressful, rather than shorter. Increased child cooperation and improved oral skills would have enabled faster feeding, however this would have been counteracted by increased responsiveness and sensitivity of feeding manner, which should increase mealtime length as the carer gives smaller mouthfuls and feeds at a pace that is easier for the child to manage.

Indeed, records of observed mealtime length in the current (see table 4-6 below) show that, in fact, mealtimes increased significantly in length following training. As mentioned above (p9), the first meals assessed may have been shorter than usual, however, the difference between researcher observations and caregiver reports continued at PTR1 and PTR2, with carers reporting meals to take considerably longer than observations revealed. As observations at PTR1 and PTR2 showed no change in meal length between the two assessments, it suggests these meals were representative and that the observations of length were accurate. Caregivers continued to report a gradual perceived decrease in mealtime length, suggesting a possible link between decreased carer stress and perception of meal length in this study.

Similarly, the actual increase in mealtime length is likely to have been due to mealtimes being less stressful and carers therefore not giving up early, as well as increased responsiveness in carer feeding manner, neither of which was counteracted by any increase in effectiveness of oral food management.

The table below illustrates the differences in caregiver perception and researcher observation of meal length. Meal length is divided into categories of ≤30 minutes or 30-60 minutes.

Table 4-6 Percentage carers in each mealtime length category

C1&C2 (*n*=16)	**BSL**		**PTR1**		**PTR2**	
	≤30	**30-60**	**≤30**	**30-60**	**≤30**	**30-60**
Reported	18	82	27	73	55	42
Observed	100	0	81	19	81	19

C2A (*n*=19)	**BSL**		**PAR**	
	≤30	**30-60**	**≤30**	**30-60**
Reported	15	85	30	65
Observed	95	5	100	0

In addition to improvements in oral feeding, the dramatic changes in child mood and cooperation during mealtimes and reductions in food refusal are likely to be linked to decreased caregiver anxiety and improved caregiver sensitivity (as described in Chapter 1, p.41). Increased caregiver sensitivity would also have enabled more accurate caregiver interpretation of their child's behaviours, with food refusal being more frequently understood as the child not being able to manage the food rather than the child rejecting it (Black, 1999). In this way a positive cycle of change is likely to have occurred with positive changes in the behaviours of child and caregiver impacting on one another.

4.2.3 Training outcomes, associated child outcomes and factors affecting compliance

Overall, it is clear that as the children were receiving no other intervention at the time of the training programme, caregiver training impacted positively on the children's nutritional status, chest health, and well-being during feeding, with additional benefits reported by caregivers. The relationship between caregiver feeding practices and child outcomes is explored below, focusing on the aspects of feeding directly related to these outcomes, namely *dietary intake, positioning and food consistency,* and *caregiver interaction style.* Factors affecting caregiver compliance are also discussed.

4.2.3.1 Diet and nutritional status

Caregiver practices and child outcomes

The most significant aspect of malnutrition suffered by children with cerebral palsy is lack of energy intake through insufficient ingestion of calories (Sullivan *et al*., 2002). Increased calorie intake was therefore a key aim in the advice and training on diet given to the caregivers in the current study, achievable through an increased calorie density of the foods eaten (by adding extra oil) and attempting to increase the quantity of food ingested. Results regarding the provision of extra oil suggest that the calorie intake had increased for at least 65% of the children in C1 and C2 by PTR1. This had reduced to 40% for the C1 children at PTR2 but had increased to 75% for the C2 children. Although food quantity increased for some individuals and decreased for others during the study period, the mean intake was the same before and after intervention, in spite of increased caregiver sensitivity and responsiveness of feeding manner. The amount of food given per day averaged at <1000ml. It is probable that with such severe feeding difficulties, the majority of the children were physically unable to manage more. It would seem that weight change was therefore brought about by calorie increase rather than changes in quantity of food intake and that the increases in oil in the diet of the C2 cohort may in part account for the overall higher level of weight increase in this group.

The quantity of drinks given, which remained severely inadequate, was likely to have been restricted by physical limitations, in the same way as food quantity.

Another aim of the study was to enhance the quality of the diet provided. Significant improvements in the content of the diets were observed with respect to vegetables and protein, although again, this was not sustained by the C1 carers beyond the first review. At PTR1, the intake of vegetables had increased to almost the level of that eaten by the rest of the family although proteins were still falling short. This may be

explained by the texture of some proteins (especially meat), which would have been difficult for the children to manage. The significance of improved micronutrient content of the diet relates to the potential impact on overall health. Data on this exists only for C2, whose health did improve during the study. (Although greater improvements in this were reported at PTR1 than PTR2, these may be accounted for by the fact that PTR2 took place during the monsoon season, a season of more widespread general ill-health).

Factors impacting on caregiver compliance

As discussed earlier in this chapter, changes in the dietary intake of the study children may have been affected to some degree by seasonal variation, as reflected in the growth outcomes of the C2A children during the harvest period. The increased intake of fruits by the C2 cohort during the mango and papaya season also suggests some influence. Other factors affecting food availability may also have impacted on caregiver ability to comply. Although the initial comparison (at BSL) between family food and the diet of the study children (see Results chapter, p.103) revealed a higher proportion of 'costly' foods (vegetables and protein) in the former, therefore suggesting a margin of potential improvement of the children's diet, financial constraints were given as one of the main reason for non-compliance, where it occurred. Indeed, proportionally more C1 caregivers reported increased financial problems at PTR2 than the C2 caregivers (50% versus 17%), which may account in part for the poor C1 results at this review.

Further improvements to dietary change may have been achieved had the programme been more similar to other nutrition education programmes in Bangladesh, which are more intensive and include more practical elements such as a cooking demonstration and shared cooking amongst caregivers (Sternin *et al*., 1998; Roy *et al*., 2005). In terms of achieving greater catch-up growth, changes in diet alone are unlikely to be sufficient however. Firstly, according to Brown *et al.* (1993), the cost implication would be 8% of the parents' daily wage to close the energy gap for a normally developing weaning-age breastfed Bangladeshi child. The cost is likely to be higher to breech the gap for disabled children who are more severely malnourished. Karim *et al*. (2003) showed that powdered micronutrient mixes would amount to a fraction of the cost of buying additional fresh foods required to meet the micronutrient gap for malnourished children in Bangladesh. They add that the bulk of fresh food necessary would exceed the intake capacity of young children. This is even more relevant for children with feeding difficulties. Furthermore, caregiver education alone is unlikely to be sufficient due to the physical impairments of the children preventing them from eating enough to enable catch-up (Johnson and Deitz, 1985; Gisel and Patrick, 1988; Sullivan *et al.*,

2000; Troughton and Hill, 2001). Ultimately, a combination of caregiver education and food supplementation might have provided a better opportunity for greater catch-up growth as, even in non-disabled children in Bangladesh, a combination of dietary education and food supplementation has been found to be more effective than caregiver education alone (Fauveau *et al*., 1992; Roy *et al.,.* 2005).

4.2.3.2 Positioning, food consistency and respiratory health

Caregiver practices and child outcomes

The importance of achieving appropriate positioning (especially head position) (Larnert and Ekberg, 1995; Gisel *et al*., 2003) as well as achieving an appropriate food consistency (Gisel *et al*., 2003) for reducing the risks of respiratory complications through aspiration caused by feeding difficulties are widely recognised. The outcomes in this study for changes to positioning of the trunk for feeding were statistically significant, even though overall positioning was still a training target for 90% of carers at PTR2. (This result was due to the fact that achieving and maintaining appropriate head positioning was problematic and the training target for positioning is a combined target for both trunk and head). Outcomes for improvements in appropriate food consistency were also significant and this remained a training target for only 33% of carers at PTR2 (in contrast to 82% at baseline). These positive changes in carer practices are likely to have contributed to the significant reductions in observed risks of aspiration during feeding and the number of reported chest-related illnesses in the children by PTR2 (in addition to carers feeding more slowly and giving smaller mouthfuls, which would also have contributed).

Factors impacting on caregiver compliance

Caregivers reported the positioning aspect of feeding to be particularly difficult. The most common reason given by the caregivers was that the child would constantly move out of the preferred position. Being able to provide adequate physical support around the head and to the lips/jaw is essential, however the scores for achievement of the latter (see Results chapter, p.158) are particularly low. Lip/jaw support is easiest to provide when a child is seated in supportive seating for mealtimes, as the caregiver's hands are more available for providing support. Most of the children, although provided with basic supportive seats, were fed in the lap, which may account for the low scores in lip/jaw support.

At first baseline, none of the study carers fed their children in a special seat (even where access to one was available), and, as reported in the Results chapter, uptake of the chairs later provided for feeding (food and drink) was limited (34% at PTR1 and

14% at PTR2). However, 68% of the caregivers at the second review said they used the chair at other times other than for feeding which is in itself was beneficial for the children in other ways.

One of the reasons given for not using seats during feeding was the fact that it took too long to seat the child. This mirrors the reasons given by the caregivers in the Reilly and Skuse study (1992) who reported that it was considerably easier and quicker to feed their children on the sofa than struggle to position the child in the recommended chair. Other reasons given by the caregivers in the current study included the fact that it was difficult to achieve and maintain a good head position in the seat, the upright position increased oral spillage, the child got irritable and restless in the chair and seemed happy on the floor, and the fact that there was not enough space in house to keep the chair. In addition to this, some of the seats became damaged through rain water and so could no longer be used. Many of the comments suggest the inadequacy of the seating systems which were not supporting the head sufficiently, and refer to practical difficutlies for householders in terms of storage issues and maintaining them during the wet season. In the light of the comments made by the caregivers in the Reilly and Skuse study (1992) who had access to high technology seats as well as the practical issues mentioned by our caregivers, one wonders whether more expensive seats that would address the head support issues would still be attractive enough and indeed 'houseable' for these families, not to mention affordable.

4.2.3.3 Caregiver interaction style

Caregiver practices and child outcomes

In this study, there were significant improvements in carer interaction style following intervention. By PTR2, the number of carers with a training goal relating to verbal encouragement had decreased from 86% to 43% and a goal pertaining to negative interaction, from 68% to 24%. Dramatic reductions in food refusal and improvements in general mood were also reported, together with significant reductions in child discomfort/distress. Considering the aforementioned recognised link between negative interaction styles, unresponsive feeding manner and child food refusal, an association between improvements in these areas and child cooperation is likely.

Factors impacting on caregiver compliance

Taking into account the strong influences of culture (Pelto *et al*., 2003; Moore *et al.*, 2005) and the impact of severe child disability on caregiver interaction style (Sayre *et al*., 2001), these results represent a highly successful outcome. Reported reasons for non-compliance in this area related to food refusal and carer anxiety that the child

should eat something or a sufficient amount, or because of not wanting to waste the food.

A positive influence on caregiver change in this aspect may be associated with the positive impact of training on the caregiver themselves. One of the key themes in regards to caregiver satisfaction following training was a newly gained sense of competence; that they now knew how to feed their child. Black (1999) discusses the link between sense of competence, anxiety and rigidity of feeding manner. In this study, as the carers reported feeling more competent, they also expressed less anxiety about their children's feeding difficulties and their feeding manner became more responsive and sensitive.

Figure 4.1 below illustrates the positive chain of change observed as a result of the training programme, using evidence from the results in terms of change that was statistically and clinically significant.

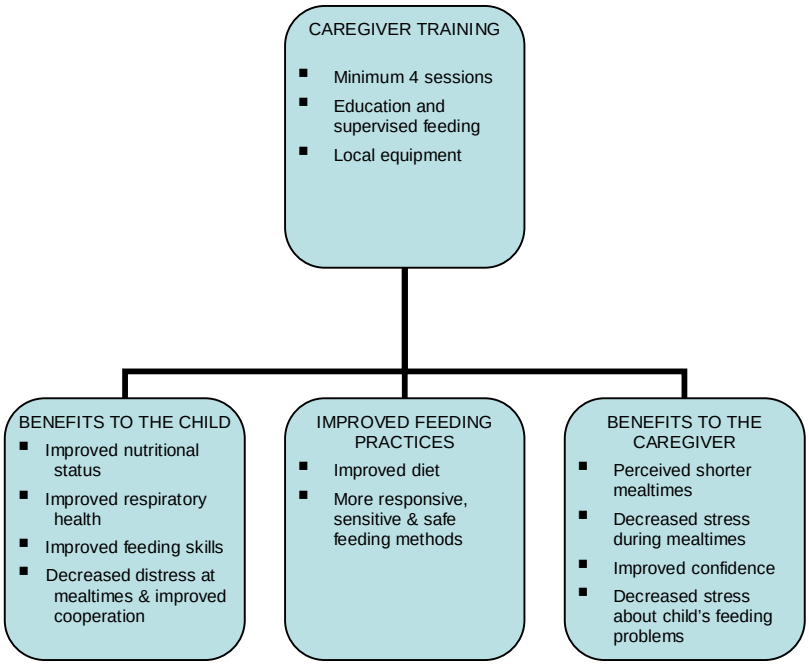


Figure 4.1 Outcomes following caregiver training

4.2.4 Training outcomes and associated family outcomes

One of the outcomes was increased interest from other family members in the disabled child and skills sharing of feeding techniques with other carers in the house, which provides the potential for increased sharing of child care and a decreased burden on the main caregiver. Another outcome was improved child health, which in turn reduces

household expenditure on medical fees and medicines and necessitates less intensive care-giving. In accordance with theories on the social determinants of health, these outcomes may have an impact on household production function and family health, due to a decrease in financial drain and an increase in caregiver time (Grossman, 1972; 2003).

4.3 Influencing factors on caregiver compliance

4.3.1 Ability to participate

As reported in the Results chapter (p.106), the C2 caregivers who dropped out before the training groups were consistently stressed to the maximum level with regards to feeding, their SRQ20 scores were the highest of the three groups, they were the least wealthy of the participants and the average number of children living at home was more than double that of the C2 participants who continued. Perceived usefulness of the training was also lower amongst this group. It is possible that these caregivers found it more difficult to participate in the full programme due the extra care burden caused by the severity of their child's condition and extra household demands. Their financial limitations may also have meant that training was less of a priority or would be more difficult to comply with, thereby reducing the motivation to attend. Motivation may also have been affected by mental well-being and perceived usefulness of the training. When asked what changes they had seen in their child, if any, since the first visit, all five caregivers reported that there had been no change, or deterioration in their child since enrolling.

4.3.2 Barriers to compliance

In terms of general issues, it was clear that caregivers' overall priorities regarding their child's development were different from the researchers', namely sitting independently, walking and talking. It also became clear from caregiver interviews that the carers' priorities with regards to their child's feeding also differed from the researchers'. They were more concerned with the ease and speed of feeding and 'normalisation' of the feeding situation whereas the researchers' priorities were primarily to improve nutrition and health and for the children to be interacted with in a sensitive and responsive manner during feeding. Recommendations for how these were achieved did not necessarily coincide with the carers' priorities and this is echoed in the reasons for non-compliance given by the caregivers in areas such as food preparation, use of special seating, speed and amount of food per mouthful, which were considered either too time consuming, not necessary or had been forgotten.

Lack of time was the most common complaint from caregivers and was reported to impact on the frequency and quantity of food given, the use of seats, food consistency (cooking rice for longer) and preparation of special foods for the disabled child, carrying out oral exercises, providing support to lips/jaw, encouraging self-feeding, and feeding more sensitively and responsively.

Transport was not reported as a major barrier to attendance in the study although it was a major issue reported by caregivers in a review of clinic-based rehabilitation services by one provider in Dhaka (McConachie *et al*., 2001). In the current study the costs of transport were provided, however, some of the carers had problems finding public transport and spent considerable amounts of time at the side of the road waiting to find a lift. McConachie *et al*. (2001) recommend services to be close to home and for home visits to be available for children who are frequently sick or in cases where the family object to the caregiver travelling.

4.3.3 Favourable indicators for positive change in caregiver feeding behaviour

Indicators highlighted as significant in previous research studies with this client group were selected here for discussion. Areas where homogeneity was too great among participants to enable statistical analysis included socioeconomic status, severity of disability, caregiver age, child health, caregiver time availability and influence of the larger family. However, some indication of association with outcomes was evident for severity of disability, caregiver time availability and the influence of the larger family. Areas where associations were possible to analyse statistically included child age, caregiver education, caregiver mental health and number of session attended.

4.3.3.1 Severity of disability

One might expect a lower achievement of appropriate feeding methods in caregivers of children with more severe physical impairments because certain changes would be physically more difficult to achieve (such as positioning and providing jaw support) and the children in this group may be more resistant to change. Conversely, in cases where children are more responsive (as in the case of less disabled children), researchers have observed a positive cycle of change, whereby change in the child encourages further change in the caregiver (Moore *et al.,* 2005). The three caregivers in this study of children with a milder degree of disability achieved high goal attainment scores, with all three scoring above 70% at PTR1 and two above 80% at PTR2.

4.3.3.2 Time availability

Pelto *et al*. (2003) report the effects of competing demands on the mother's time on their compliance with advice with regards to feeding practices. The majority of caregivers in this study reported sometimes being short of time. Lack of time was given as a reason for non-compliance in many aspects of feeding advice. Two caregivers reported always being short of time. The compliance scores for these two were 50% and 47.8% at PTR1; 55.3% and 56.8% at PTR2, both below the group mean.

Use of appropriate utensil and interaction style were not reported to be affected by time constraints however. At the same time, the areas of greatest compliance were feeding manner (amount per mouthful, utensil used, pacing and delivery) and interaction style. This suggests an association therefore between time implications and caregiver compliance with respect to specific aspects of feeding.

4.3.3.3 Influence of the larger family

Pelto *et al.* (2003) talk about the influence of the larger family on caregiver compliance with regards to training in feeding practices. The C1 and C2 caregivers who lived in joint families (*n*=6) reportedly felt well-supported (with one exception) and achieved average overall compliance scores of 68% (three of which were over 75%). In terms of the potential for negative family influence, one caregiver dropped out before training began because her husband and brother-in-law uncle did not think she should attend.

4.3.3.4 Child's age

The age of the child can be a factor in the success of introducing new care practices as older children are known to be more attached to their habitual patterns of behaviour and therefore resistance to change is common. It is also possible that caregiver motivation is lower when supporting an older child, as the hope of 'recovery', which is common in the early years, has diminished over time. As reported in the Results chapter (p.160), an inverse correlation was found in this study between child age and caregiver goal attainment with caregivers of younger children achieving higher scores. Early identification and management of feeding difficulties is recommended in the literature (Gisel and Patrick, 1988; Motion *et al*., 2002).

4.3.3.5 Caregiver education

Lower levels of caregiver education were found to be correlated with higher levels of training need at baseline assessment, supporting the literature on carer education and responsiveness of feeding practices (Guldan *et al*.,1993). However education was not found to be correlated either with compliance scores or level of need remaining following training, and therefore did not impact significantly on carers' ability to learn.

4.3.3.6 Caregiver mental health

As mentioned in Chapter 1 and above, caregiver mental health, especially anxiety and depression, is an important influence on responsiveness of feeding style (Coulthard and Harris, 2003; Hurley *et al*., 2008). Maternal depressive symptoms have also been linked to lower adherence to therapy (Bartlett *et al*., 2004). In the current study

however, no correlation was found between carer scores for mental well-being and training outcomes.

4.3.3.7 The number of sessions attended

The minimum number of contacts with caregivers was two advice sessions plus two group training sessions (for those who attended training). The majority of C1 and C2 caregivers attended four group sessions or more with only five caregivers attending fewer than this. Goal attainment scores for those who attended more than four sessions were on average higher than those who attended two-three sessions, however the difference is not significant and as the numbers in this latter group are low, the validity of a comparison of outcomes between the two groups is questionable. Nonetheless, those C1 and C2 caregivers who received the minimum of two advice sessions plus two training sessions did achieve significant improvements in feeding practices. This compares with the findings from the study by McConachie *et al.* (2000) who evaluated training to Bangladeshi mothers of disabled children in which change was seen after a minimum of four sessions. In the current study, both caregiver knowledge scores and the degree of behaviour change achieved following *advice only* were significantly lower than those achieved following *advice plus training*. In addition, the difference in overall compliance scores between the C1 and C2 cohorts may further suggest that length of input makes a difference to outcomes.

Statistical change following *advice only* was achieved in three aspects of feeding (positioning (partial), food consistency and utensil), however, none of these changes achieved clinical significance. Likewise, significant change was achieved in only four of the child outcomes for this group (as opposed to nine variables following *advice plus training*) and the impact on caregiver stress was significant only in those who received training.

4.4 Strengths and limitations of the study

4.4.1 Study design

4.4.1.1 Sample size

Although the study focused specifically on children with cerebral palsy and feeding difficulties, the literature shows that this group includes a fairly broad spectrum in terms of severity and presentation of disability and feeding difficulties. The search for a homogenous sample in this study perforce resulted in a relatively small sample which in turn restricted the extent of analysis possible with respect to the quantitative data collected. The advantage of this small sample size was that it enabled detailed information and knowledge to be gathered about each child-caregiver pair.

4.4.1.2 Seasonal variation

Seasonal variation is a recognised complicating factor in health and nutrition studies conducted in Bangladesh (Brown *et al.*,1982; 1985; Rousham and Mascie-Taylor, 1995) and should be controlled for as far as possible. One means to achieving this strategy in the current study would have been to coincide the C2 non-intervention phase with the C1 intervention phase. However, simultaneous recruitment into both cohorts was not possible as the recruitment phase would have needed to be extended to the point of invalidating the data collected on the first children recruited, before starting their training. Simultaneous recruitment would also have required C2 participants to wait longer between assessment and the start of their group training programme. This would have increased the risk of drop-out due to the migrant nature of urban slum dwellers or due to loss of motivation to attend, caused by waiting.

4.4.2 Assessment and intervention methods

4.4.2.1 Multidisciplinary input

One of the strengths of the study was its location within a Child Development Centre and the availability therefore of input from a variety of professionals. For example, the medical assessment was particularly useful in screening for epilepsy, for which treatment was available. Epilepsy can seriously impact on a child's feeding abilities and increase the risks of aspiration, as was observed in study children where its management was problematic. The availability of a trained counsellor was also helpful, especially as data collection involved the use of a mental health screen, after which psychological support should be offered if required. Finally, the fact that the therapists had been trained in generic therapy skills was an advantage in running the training

groups as they already had experience in positioning and handling children with CP and some training in nutrition.

A further benefit to being located in the CDC was the resultant increase in staff skills and awareness with regards to the feeding needs of children with CP, having been involved in the study. Furthermore, as this CDC is also considered the centre of excellence in rehabilitation services in Bangladesh, training will be rolled out to other satellite CDCs around the country.

Finally, it was very important that the feeding service was located in a centre offering the full range of services to disabled children and their families. In this way, children and carers could access a multidisciplinary service, including medical treatment as well as general rehabilitation, which many had never received previously.

4.4.2.2 Combination of home visits and clinic-based service

A further strength of the study was the combination of home-visiting with a clinic-based service. Home visiting allowed for a naturalistic assessment of need and observation of the opportunities and barriers the caregiver may face with regards to compliance. It allowed the demonstration of advice 'in situ', and also helped to build trust between the researchers and the families. The clinic on the other hand, allowed for the involvement of the multidisciplinary team, as well as providing a forum for carers to meet.

4.4.2.3 Researcher representation and translation issues within the study

The representation of the researcher in this study was an unavoidable factor, in a similar way to all research involving qualitative methods (Mantzoukas, 2004). This applied not only to the data collection process, but also to data analysis and interpretation (Finlay, 2002). Furthermore, as this study represents 'practice-close' research for the PI (i.e. the researcher was investigating a clinical area close to their own area of practice) representation was more likely. An awareness of the potential influence of the consequent preconceptions and manner of interacting with the participants was therefore important in the assessment procedure (Lykkeslet and Gjengedal, 2007). For this reason, attempts were made to use structured methods where possible. Interviews were conducted principally by the RA, but the fact that two people were present at interviews provided some degree of monitoring. The RA also participated in the analysis of the qualitative answers, and independent experts were used to validate post-hoc where possible.

Even though participant responses may have been influenced by the presence of the PI (Hitchcock and Hughes, 1995), the fact that both researchers were present during interviews was considered a specific strength in the assessment process. Not only did it permit the PI, as well as the RA, to observe the behaviour of the participants, but it was also beneficial with regards to translation issues. As in any dual-language research, there is a risk of reducing the accuracy of the information recorded (Krueger, 1993). In this study, the PI's presence at interviews, combined with some knowledge of both languages and real-time translation from the RA, allowed for clarification of responses and monitoring for accuracy. Real-time translation in turn allowed the PI to participate in the interviews, the advantages of which are outlined in the Methods chapter (p.77). Although it is commonly recommended to record interviews in qualitative research (Cresswell, 2003, p190), recordings were not made due to the preferred use of real-time translation.

However, as Esposito (2001, p572) states, "the process of translating the researcher's questions into a form that is understood by the participant and then translating the participant's responses into a form that is understood by the researcher is one of the biggest challenges faced by cross-cultural researchers'". He goes on to state that translations cannot be made word-for-word and as all concepts are universal, not everything is translatable.

Common pitfalls in translating Bangla to English included ambiguities over the word for eating & drinking, as only one word is for both meanings in Bangla, the use of the English word 'healthy' which was commonly used to mean well-nourished rather than in good health, and distinguishing between *'more'* versus '*too much'*, *'won't'* versus *'can't'* and *'need'* versus *'want'*. Establishing the appropriate translation for the range of caregiver feelings reported was also required and much time was spent on this during piloting. In terms of threat to validity, it should be noted that a study examining the influence of translation on the validity of findings from in-depth interviews of non-English-speaking Chinese women (Twinn, 1997 cited in Esposito, 2001) found that even though a number of differences existed in the English and Chinese transcripts, there were only minor differences in outcome of the analysis, with the same major themes being generated from the data in both languages.

4.4.2.4 Observer effect

The influence of the researchers and their relationship to the persons being observed in terms of its impact on their behaviour is well recognised (Lykkeslet and Gjengedal, 2007). This is sometimes referred to as 'observer effect' and is particularly relevant in

this study to the mealtime observations. This 'effect' may have been increased in this study by the presence of a foreign PI as well as the RA, however, reasons justifying the presence of both are outlined above. Hammersley & Atkinson (1996) and Bjørndal (2004), as cited in Lykkeslet and Gjengedal (2007), suggest that rather than try to eliminate the impact of the researcher, it is better to be reflect on it and try to understand it. Analyses of the results of this study attempt to take these factors into account through triangulation of data obtained through observation as well as interviews and objective measures and where these differ, the impact of the researcher is included in the discussion.

4.4.2.5 Reliability of information

The fact that the study took place in a resource-poor environment necessitated low-technology methods of data collection. Information had to be obtained through clinical examination conducted in the community, with limited equipment, rather than through the use of instrumentation and invasive procedures, which are commonly used in high technology, well-resourced countries. These include objective measures, such as tests of pulmonary function (recommended by Gisel *et al*., 2003), triceps skin fold (recommended by Samson-Fang and Stevenson, 2000) and videofluoroscopy, which is considered the gold standard technique in adults and 'important' in the assessment of risk for pneumonia in children (Taniguchi and Moyer, 1994 cited in Arvedson and Brodsky, 2002).

Nonetheless, alternative ways to diagnose aspiration, leading to a reliable diagnosis have been suggested in the literature. Waterman (1992) advocates use of the combined results of clinical observation (observed coughing), history of episodic aspiration and history of occasional pneumonia. Taniguchi and Moyer (1994) suggest using the combined results of observed clinical signs, the identification of GOR, a diagnosis of cerebral palsy and failure to thrive. In the current study it was possible to use the combined results of clinical observation, history of chest-related illnesses, diagnosis of cerebral palsy and nutritional status. The assessment of GOR was variable however, again due to the absence of objective measures as well as staff expertise and was therefore not a helpful contribution to the diagnosis of aspiration. The variability of the diagnosis of GOR was regarded as a hindrance more in terms of its own management, which can improve feeding ability and the 'feeding experience' to a great extent and may have improved the outcomes of some children therefore.

With regards to calculating food quantity, standard methods involving a 24 hour food frequency questionnaire and portion sizes were used, however, this did not account for

the intake of finger foods, food lost through oral spillage or left uneaten at the end of the meal. The results regarding the quality of the diet rather than the level of intake are therefore more useful in the current study.

The degree of honesty with which carers felt they could speak to us was naturally an issue in terms of the validity of the information gathered through interviews. On one occasion a caregiver changed her description of how she felt during feeding, within a very short space of time and before group intervention had begun. When asked at home how she felt during feeding replied that she felt angry, but then when asked again in the hospital, she said she only felt upset. When reminded of what she had previously said she embarrassedly admitted to feeling angry as well. This incident illustrates the high level of clarification and checking which took place throughout interviews. On other occasions however, carers would admit to negative behaviours even after training, and when these had not been evident during the mealtime observation. This fact, together with the potentially shocking nature of many of the feelings reported by carers suggests that for the most part, reports were candid.

4.4.3 Study analysis: combining C1 and C2

There were two possibilities for combining the data from C1 and C2 for analysis. One approach would have been to combine C1's initial assessment with C2's post-advice review (PAR), as the intervention from these two points onwards was the same for both cohorts (see figure 4-2 below).

C2 had already received one advice session and 3-4 months practice time before reaching their PAR, and it was felt therefore, that data collected at the PAR would not be a true reflection of their starting point. It was thus decided to combine the data from the initial assessments to establish the C1 and C2 combined baseline and to investigate for any significant differences in outcome between the groups at PTR1 and PTR2, as discussed below.

C1 **April 2005** **-Feb 2006** 10 months	**Baseline 1 (BSL)** Initial assessment & advice	**Training groups** 2 1/2 months	**Review 1 (PTR1)** 1st post-training review	**No input** 4-5 months	**Review 2 (PTR2)** 2nd post-training review	
	n=16	*n*=13	*n*=11		*n*=12	

C2 **July 2005** **-Sep 2006** 14 months	**Baseline 1 (BSL)** Initial assessment & advice	**No input** 3-4 months	**Baseline 2 (PAR)** Post advice review & advice reiterated	**Training Groups** 2 1/2 months	**Review 1 (PTR1)** 1st post-training review	**No input** 4-6 months	**Review 2 (PTR2)** 2nd post-training review
	n=21		*n*=20	*n*=15	*n*=13		*n*=12

Figure 4.2 Study design

In terms of caregiver compliance, there was a similar degree of change on most measures between carers in the two cohorts, although the generally higher starting scores for C2 carers led to higher PTR2 outcomes. Nonetheless, compliance scores were significantly higher in the C2 cohort. This may have been accounted for by the additional advice session at their PAR assessment and extra practice time between baseline and the PAR. However, the learning from this would have been superseded by the subsequent learning from attending the training course and by PTR1, caregivers in both groups had achieved a similar level of knowledge. An additional advantage may have been that the training itself improved due to lessons learnt in training the C1 cohort. More important may be the fact that these carers scored significantly higher in responsiveness at baseline suggesting their circumstances were more conducive, thereby leading to greater overall responsiveness at the end of training. In terms of socio-economic factors, there appears to be no potential for positive influence. C2 carers, if anything, had a slightly lower level of schooling, less income and higher stress levels. They did, in contrast, have more supportive home environments, their disabled children were consistently younger (which is positively correlated with caregiver compliance) and more positive in mood, they had fewer other children living at home, and three of the C2 children were less physically disabled.

Overall patterns of change were similar for the two cohorts with some small variations. One main area of difference was that C1 caregivers did not sustain changes in the diet, nor increases in food intake achieved at PTR1. A possible reason for this may have been variations in food security between the families in C1 and C2, which, as mentioned

previously, can vary significantly between different slum areas in the city (Helen Keller International, 2002). Reports from caregivers at PTR2 suggest that food security may have had an impact, with 40% of C1 caregivers versus 25% of C2 caregivers reporting it to be an issue at PTR2. These factors may also have contributed to the higher increases in WAZ amongst the C2 cohort, although these may also be accounted for by the greater time period between first assessment and final review.

Overall, the results suggest that the study design was not the major factor in the differences in outcome between the two cohorts.

4.4.4 Tools developed for the study

A strength of the study was the development of new tools for working with this client group, which not only served well for the purposes of the study but can now be modified, validated and adapted for use in other resource-poor settings. The most important assessment tools developed were the Mealtime Observation Schedule (FORM 7) and accompanying Training Needs Schedule (FORM 8).

The advantage of having two assessment schedules was that the first served as an 'objective' record of feeding behaviours, whilst the second presented a clinical evaluation of appropriateness of feeding behaviour. As a pair they provided a combination of raw data plus clinical judgement in an environment where objective measures were otherwise unavailable.

There are various ways in which these tools could be improved however and it is recommended that they be modified and validated before future use.

Chapter 5

Conclusions and Recommendations

5 Conclusions and Recommendations

5.1 Conclusions

5.1.1 Need for universal awareness of feeding issues among children with CP

The issues for children with feeding difficulties and their carers are universal and common themes exist for both, regardless of availability of resources, education, socio-economic circumstances or culture. The five key issues are as follows.

1. Deficiencies in diet and underfeeding.
2. Inappropriate food consistency, increasing the risks of aspiration and reducing nutritional intake.
3. Inappropriate positioning, increasing the risks of aspiration and limiting the child's skills of independence.
4. Unresponsive and insensitive feeding practices.
5. Inadequate fluid intake.

As a consequence, levels of child malnutrition and morbidity are high, as are the risks of premature death from disease and respiratory problems, the commonest cause of death in children with CP (Reddihough *et al*., 2001). In addition, their carers feel stressed, short of time, and uptake of services is limited, even where they are easily available.

Environmental circumstances, where individuals are living in poverty, however, affect the degree of severity of the child's nutritional and health status, which is exacerbated for children living in hot countries, where infection and dehydration are common.

Other factors however, are equally significant to child and caregiver, where the level of disability is the same, regardless of environment. This suggests a global negligence to meet the needs of this vulnerable and marginalised population and a lack of interest and attention given to the issue.

5.1.2 Effectiveness of the intervention

In spite of environmental circumstances, cultural barriers and level of priority given to feeding, carers of a disabled child living in Bangladesh, who have minimal formal education and live in abject poverty are able to change care-giving practices significantly as a result of training with positive consequences for both child and caregiver. In this study, a minimum of four training sessions resulted in the following:

- A marked reduction in the risk of aspiration during feeding and the number of chest-related illnesses.
- Improved nutritional intake and improved or maintained nutritional status in the majority of cases.
- A noticeable increase in child cooperation during mealtimes and overall mood.
- A marked reduction in caregiver stress regarding their child's feeding difficulties.
- A clear reduction in distress experienced by the child and caregiver during mealtimes.

Through the training, it was possible to make a significant contribution to the children's rights to ***'maximum heath, self-reliance and dignity'*** (The United Nations convention on the Rights of the Child, 1989, article 23)

Better outcomes can be expected the longer the training period (minimum of four sessions), the younger and less severely disabled the child, when the carer has more time available for care-giving and when they are supported by the larger family. In terms of motivation to attend, this may be affected by mental well-being and perceived usefulness of the training as well as financial and care burdens.

Nonetheless, carers can make significant changes following just two advice sessions with regards to the following:

- Aspects of positioning for feeding.
- Appropriate choice of utensils.
- Frequency of chest-related illnesses.
- Independence in feeding.
- Improvements in child mood.

In terms of the intervention provided in this study, greater effectiveness still needs to be achieved in assisting caregivers in achieving optimal support for positioning during feeding and further increasing fluid intake and catch-up growth.

Continued experimentation and discussion with doctors, therapists and caregivers are necessary to address these issues. With regards to catch-up growth, the recommendation as outlined in the previous chapter is for education plus supplementation, however, the degree to which education plus food supplementation would achieve catch-up growth in this population is still to be assessed. Furthermore, the issue of access to free supplementation needs to be addressed as access to

mainstream services is difficult for this population. Reasons cited by managers of nutrition programmes in Bangladesh include the difficulty in transporting the child, the possible problems with the child managing the food that is given out (eg. fortified biscuits) and the fact that some services target acute malnutrition caused by diarrhoeal disease alone.

As mentioned in the Discussion chapter (p.197), intervention of this nature may benefit the whole family through the combined benefits of the potential for increased sharing of child care coupled with improved child health and the impact of these on family finances and availability of caregiver time, leading to increased household production function (Grossman 1972, 2003). The potential size of this effect, as a result of caregiver training in feeding their disabled child, should be investigated.

5.1.3 Products of the Study

- A resource of assessment tools and training materials now exists for staff working with this population, which can be modified and validated.
- The training programme and potential list of caregiver goals can both be adapted in accordance with the number of sessions carers will attend.
- Priority can be given to the key practices affecting diet and calorie intake, fluid intake, safe and responsive feeding and excluding practices which are less achievable or less important, such as the application of oral-facial exercises, the thickening of fluids and the management of spillage with drinks.
- An educational video drama is now available for distribution to any services which may have contact with carers of children with CP and feeding difficulties in Bangladesh. This can be used both for staff and caregiver training, and for prevention as well as intervention.
- There also now exists a body of health professionals within the Child Development and Neurology Unit at the Dhaka Shishu Hospital who are skilled in running caregiver feeding groups and, due to the success of the study, the head of the unit has insisted the groups designed in this study are integrated into the weekly programme at the centre.
- Another consequence has been the unit's pursuit of additional input for their feeding service and the successful application of a British Council grant to fund a partnership with therapists from the UK for this purpose. The first visit has already taken place, facilitated by the PI of this study, and from which an ongoing strategy for staff and service development within the feeding services provided by the unit and associated satellite centres has been designed. At the same time, modifications were made to the mealtime observation form (FORM 7) and training

needs schedule (FORM 8), developed for the current study, for use within the centre.

- Preliminary discussions have taken place between the PI, a UK-based nutritional research organisation in the UK and one in Bangladesh to set up a study that would evaluate the potential for using a locally produced nutritional supplement to aid growth catch-up in the CP population in Bangladesh.
- Discussions have also taken place between the PI and the Bangladesh committee for the implementation of the WHO/UNICEF joint strategy, The Integrated Management of Childhood Illness (IMCI; World Health Organisation and UNICEF, 1999), to raise awareness and campaign for the inclusion of children with disabilities in the local strategy.

The materials and expertise can be used to roll out feeding services to such children and families in Bangladesh, and modified as required for other resource-poor settings, not only in Bangladesh. Furthermore, if the research into the production or modification a local food supplement is successful, this can be incorporated into any intervention package and again, modified for use in other settings.

5.2 Recommendations

5.2.1 Recommendations: training

- The first recommendation is for the refinement and publication of the training materials developed in this study in order to provide a resource for training staff as well as carers. Particular attention should be paid to training on positioning and increasing fluid intake.

- Training for staff in child development centres should include the assessment of growth and growth monitoring alongside training on feeding difficulties.

- Based on caregiver feedback, training methods should always employ the use of demonstration and supervised feeding as well as formal teaching.

- Once the training resources are available, the programme should be rolled out at all levels. This includes basic training to community health workers to be able to identify the problem, to give preliminary advice and to know who and how to refer the child and caregiver on where possible. It also includes training the multidisciplinary team at the community clinic and hospital level (rural and urban) including tertiary.

- Individuals should be offered a minimum of four sessions of training. In addition, ongoing, regular access to services is necessary in order to maintain lessons learnt, increase skills further and modify advice according to the changing needs of the children. An ongoing service also provides the opportunity for regular support to caregivers and the ability to monitor the child's health and growth.

- Advice to caregivers should minimise the impact on caregiver time as well as emphasising the relevance of the advice given in order to promote caregiver compliance.

- Additional information arising from further relevant research, such as the development of food supplements, should be incorporated into any training programme.

5.2.2 Recommendations: policy and programme development

- In view of the lack of available services and awareness of the needs of this population, advocacy is urgently required to increase awareness and support amongst governments, health service commissioners and health providers on a global level regarding the needs of children with disabilities and feeding difficulties and their caregivers.

- The lack of availability of services for children with disabilities and feeding difficulties in mainstream services requires their active inclusion in national strategies on child health and nutrition, such as The Integrated Management of Childhood Illness (IMCI; World Health Organisation and UNICEF, 1999) and the UN agencies/international NGOs partnership initiative for the management of moderate malnutrition (Kraemer, 2008).

- The specialist needs of these children over and above those of the non-disabled population requires capacity-building at all levels of service delivery to enable mainstream services to provide the appropriate input to this population. I suggest a three-tiered approach, such as that used in the IMCI. This would improve both family and community practices as well as strengthen the health system and health workers' skills.

- Assessment for and the treatment of certain medical issues is necessary in the management of children with feeding difficulties. These include:
  -Chest health.
  -Gastroesophageal reflux.
  -Epilepsy.
  -Nutritional status.
  -Hydrational status.

  In addition to medical issues, it is essential to ensure that methods for providing physical support to the child, appropriate nutrition and use of positive interaction skills are included in an intervention programme.

  Any input addressing feeding difficulties should therefore be provided by a multidisciplinary team, especially in an environment of widespread malnutrition, high morbidity and risk of dehydration and in a culture were feeding methods are generally unresponsive.

- It is further recommended that a feeding programme be located within a generic therapy service where interventions addressing the wider rehabilitation needs of the child are available.

- Models promoted by researchers, such as McConachie (1994) and Mobarak *et al*. (2000), confirm the evidence from this study that programmes should include family members and goals should address the well-being of both child and caregiver.

- Results from the study by McConachie *et al*. (2000) and this study show that a combination of home-visiting and clinic-based services should be available to families with children with feeding difficulties. In the case of clinic visits, however, the transport issues for the child and caregivers should be considered.

- The association between child age and outcomes for both carer and child in this study supports the widely held view (Gisel and Patrick, 1988; Motion *et al*., 2002) that the emphasis in services for this population should be on early identification and intervention.

- The nutritional status of the study children at the end of the intervention programme shows that research is urgently needed to investigate the appropriateness, effectiveness and sustainability of providing locally produced food supplements to this population in Bangladesh, in addition to education on diet.

- Research needs to examine the impact on household production function and family health of programmes addressing the feeding needs of children with disabilities in Bangladesh and other countries.

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Appendices

Disability Feeding Study

Dhaka Shishu Hospital

Child Development and Neurology Unit

Information for Carers

Hello, my name is Shilpi. I am working on a research project at the Dhaka Shishu Hospital. The other members of the training team are a therapist from the UK and 3 therapists from the Shishu Hospital. The purpose of the project is to help us find the best way to teach mothers to feed their children with Cerebral Palsy who find eating and drinking difficult. We hope that by training the mothers, the children will find eating easier, put on weight, be healthier, happier and more able to do things. We also hope that it will make the mothers feel less worried about their child's feeding difficulties.

For our study, we firstly need to assess the child's feeding problems, after which we will give mothers 6 training sessions lasting 2 hours each, to teach them about the type of food their child needs to eat and how to feed them. The training will be done in groups of 6 women so that you all have a chance to talk about the problems you are having and help one another find solutions.

If you are interested in being involved in the study, we will need to ask you some questions now about your child's feeding difficulties, and measure your child's body.

You will also need to take your child to the Shishu Hospital for a short medical examination.

If, after the medical examination, we decide we would like you and our child to participate in the study, will need to come to your house to ask you some more questions and watch you feeding your child. The feeding observation will be videoed.

You will then be allocated to a group for 6 weeks training. When the training is finished, we will come and see you again at home two more times. On these visits we will ask you questions again and again video your child eating.

The videos will not be shown to anyone else here. They may be seen by someone in London who wants to check we have done our job properly.

If you participate in the study, you will be helping us a lot, and hopefully, thousands of other mothers and children in the future, who have similar problems.

In return we will give you some special equipment you need to feed your child. We will also give you 350Tk for your travel expenses to and from the hospital, and a photograph of you and your child. You will need to bring a small amount of food with you to feed your child during the training sessions.

I certify that I have read/been read this document, and consent to being a participant in the study, which includes being videoed feeding my child.

Signed and date _____

Info.consent300005

SCREEN for DISABILITY FEEDING STUDY

Selection for study requires answer YES to all of the below:

	Yes	No
Child is aged 1-10 yrs	☐	☐
Child has moderate or severe CP	☐	☐
Does the child need help with any of these:		
Holding head up		
Sitting		
Walking		
Feeding itself		
Child does not appear to have genetic or progressive condition	☐	☐
Child is semi-fully weaned	☐	☐
Child has a feeding problem	☐	☐
Does the child have any of the following:		
Problems eating solid food		
Coughs on food or drink		
Meals take a long time		
Need to force feed		

Screened by:_____

Location:_____

Date:_____

TO BE COMPLETED BY RESEARCH ASSISTANT:

Date of home assessment _____

Date of 1st group session _____

Date of doctor's assessment _____

060406

BIODATA

Child's name:	**Main caregiver:**
Gender: M / F	**Caregiver's name:**
Child's age: _____yrs _____mths **DOB: _____**	**Father's name:**

Address:

City ☐ **Town** ☐ **Village** ☐

House no., street & area of city

Name of village:

Name of nearest town:

Name of city / town:

Journey time to nearest town:

Thana name:

Thana name

Tel number:

Tel number

Access:

1. Bus ☐
2. Car / van ☐
3. Bicycle / rickshaw / motorcycle / CNG ☐
4. Boat ☐
5. Foot ☐

Estimated journey time to Shishu:

TO BE COMPLETED BY RESEARCH ASSISTANT:

Child ID

Anthropometrics:

	Initial Assessment	1st review	2nd review
Weight			
Armspan			
MUAC			

260405

FORM 1

Data entry child ID no: _____

Socio-demographic information

Child's name: _____ **101 Date:** _____

Household characteristics

102.1 **Presence of father**	1. Living with family whole time	2. Away part-time	3. Living abroad	4. Divorced/ separated	5. Dead
102.2 **Presence of mother**	1. Living with family whole time	2. Away part-time	3. Living abroad	4. Divorced/ separated	5. Dead
103. **Who child living with**	1. Nuclear family	2. Joint (father's)	3. Joint (mother's)	4. Joint (other)	
104. **Do other relatives live close by?**			1. Y	2. N	
105. **Family members in house / quadrant (in relation to the child)**				Number:	
105.1 Grandparents / Gt G/parents					
105.2 Parents					
105.3 Uncles					
105.4 Aunts					
105.5 Brothers-in-law					
105.6 Sisters-in-law					
105.7 Older siblings					
105.8 Younger siblings					
105.9 Older cousins / nieces / nephews					
105.10 Younger cousins /nieces / nephews					

106. **Who is/are the head of household/ main decision-maker(s)?** (multiple)	1.G/father	2.G/mothr	3.Father	4.Uncle	5.Mother	6.Other _____

Employment

107. **Who are the main earners / workers in the family?** (multiple)	1.G/father	3.Father	5.Mothr	4.Uncle	6.Aunt	7.Other
108. **Main earners' occupations**						

109. **Is / are the job**	1. Regular / secure	2. Irregular	3. N/A
110. **Does ill-health often prevent them from working?**	1. Y	2. N	3. N/A
111. **Mother's/main feeder's occupation**			

Education of main feeder

112. **Who is the main feeder?**	1. Mother	2. Grandmother	3. Sibling	4. Other :

113. **Is the main feeder literate** (can read and write – more than her name?)		1. Y	2. N
114. **If not, is any other member of the family literate?**	1. Y	2. N	3. N/A
115. **Main feeder's age**			yrs
116. **Did main feeder go to school?**		1. Y	2. N

1

FORM 1

117. If yes, what grade did she study up to? **1 point for each class: School 1-10, SSC=11, HSC=12, BA level=13, MA level=14**	

Food procurement

118. **Where does your family get its food ?**	118.1 Home-grown	1. Y	2. N
	118.2 Market	1. Y	2. N
	118.3 Food programme	1. Y	2. N
	118.4 Other	1. Y	2. N
119. **Who decides what food to buy for the family?**	119.1 G/father	1. Y	2. N
	119.2 G/mother	1. Y	2. N
	119.3 Father	1. Y	2. N
	119.4 Mother	1. Y	2. N
	119.5 Other	1. Y	2. N
120.1 **Do you know how much money on average is spent on food each**	120.1 Day	1. Tk	2. DK
	120.2 Week	1. Tk	2. DK
	120.3 Month	1. Tk	2. DK

120.2 **Who controls the household money?**	1.G/father	2.G/mothr	3.Father	4.Uncle	5.Mother	6.Other
121. **How much food do you store?**					1. None	2. Some

122. **Who decides what food to give this child?**	1.Caregiver (alone)	2.Caregiver & other: _____	3.Someone else: _____

HYGIENE awareness

123. **How many times do you/others cook for the family in a day?**				
124. **If you're preparing (> 5 mins) additional food for this child, how many times do you do this in a day?**				
125. **How long do you leave food out (of the fridge) after cooking, before your child eats it?**	1. 1/2 day	2. whole day	3. day + night	4.N/A
126. **How many times do you reheat the food this child eats?**				

127. **Do your family clean their teeth daily?**	1. Always	2. Sometimes	2. Never
128.1 **Do you clean this child's teeth daily?**	1. Always	2. Sometimes	2. Never
128.2 **How?**			

129.1 **Do you know your household's yearly earnings?**		1. Y	2. N
129.2 **If yes, what are they?**		1. Tk	2. N/A
130.1 **Did your household take out a loan last year?**	1. Y	2. N	3. DK
130.2 **If yes, how much was it for?**	1. Tk	2. DK	3. N/A

131. **Poverty Mapping Score** [ ]

2

FORM 2

Bangladesh Health Equity Watch

Poverty Mapping Questionnaire

1. **Identification**

1.1. Village Name: _____
1.2. Bari Name: _____
1.3. Name of the household head: _____
1.4. Name of the respondent (if other than Head): _____

Characteristics of the head of household

1.5. Primary occupation of the head: _____

1.6. Education: _____ years completed

2. **Assets and selling of menial labour**

2.1. Does any member of this household own any of the following?

Television	Yes - 1	No – 2
Radio	Yes - 1	No – 2
Watch/Clock	Yes - 1	No – 2
Table/Chair	Yes - 1	No – 2
Quilt/Blanket	Yes - 1	No – 2
Khat/Chouki	Yes - 1	No – 2

2.2. How much total land the household owns?
3.2.1 Homestead: _____Decimal
3.2.2 Cultivable: _____Decimal

2.3. Does any member of the household sell menial labour to make living?

Yes - 1	No – 2

1

3. **Lack of Education**

3.1 What is the level of education the head of the household had passed?

Never been to school	3
Primary or less	2
Above primary	1

3.2 What is the level of education the father of the household head had passed?

Never been to school	3
Primary or less	2
Above primary	1

3.3 How common is reading ability of the household members aged 10 years and more?

Half or more can read	1
Less than half can read	2
None can read	3

3.4 How common is writing ability of the household members aged 10 years and more?

Half or more can write	1
Less than half can write	2
None can write	3

4. **Lack of Health**

4.1. How frequently do the household members on average suffer from illness or ill health?

Quite frequently (once or more in a month)	3
Now and then (three or more times in a year)	2
Very rarely (less than three times a year)	1

4.2. In case of illness of the household members, how often an allopathic doctor is contacted?

Most of the time (in more than half of the cases)	1
Now and then (half or less of the time)	2
Once in a while or never	3

4.3. In case of dairrhoeal illnesses of the household members, how frequently ORS is administered at home?

Most of the time	1
Sometimes (half or less of the time)	2
Once in a while	3

4.4. How common it is to wash hands with soap after defecation among the household members?

Most of the time (more than half the time)	1
Now and then (half or less of the time)	2
Once in a while	3

5. **Social isolation**

5.1. How intensely any member of the household participates in the samajik/community activities?

Highly actively	1
Not so actively	2
Not active at all	3

5.2. To what extent the members of this household can expect to receive financial help and social support from relatives/friends?

Full support	1
Some support	2
No support at all	3

5.3 How often do you/any member of the household visit Dhaka/Chittagong city?

Quite frequently (once a month or more)	1
Not so frequently (once in 3 months or less)	2
Not at all/very rarely (once in a year or less)	3

5.4 How often any member of the household reads newspaper or listens to radio or watches television?

Quite frequently (almost everyday)	1
Not so frequently (once in a month or more than once in three months)	2
Rarely (once in three months or less)	3

6. **Lack of Shelter**

6.1 Does this household own any shelter anywhere?

Has house (land and house)	1
Has land no house or has house no land	2
No land no house	3

6.2 What the roof of the largest dwelling is made of?

Pucca	1
Tin/Tiles	2
Straw/polythene	3

6.3 How many *ghar* (structure/room) the house has?

One	3
Two	2
Three and more	1

6.4 What type of latrine does the household own?

Sanitary with safety tank	1
Non-sanitary	2
Does not own any	3

7. **Lack of Food**

7.1 How frequently it so happened during the last 12 months that at least some of the household members couldn't have three (breakfast, lunch, dinner) meals (Rice/Ruti) a day due to shortage of food?

Quite commonly (four or more days in a month)	3
Now and then (once or less in a month)	2
Very rarely/Never	1

7.2 How commonly meat is cooked in this household?

Quite commonly (15 days or more in a month)	1
Now and then (less than 15 days a month)	2
Not at all	3

7.3 How commonly lentil or any kind of legume is cooked in this household?

Most of the days (al most everyday)	1
Now and then (four or less time a month)	2
Not at all/rarely	3

7.4 How frequently milk is consumed?

Quite commonly (almost everyday)	1
Now and then (four or less no. of days in a month)	2
Not at all/very rarely	3

8 Lack of Clothing

8.1 How frequently it happened during the last 12 months that at least some household members had to wear torn/second hand clothes due to shortage of clothing?

Most of the days	3
Now and then	2
Not at all	1

8.2 Do all the members of the household have three or more sets of clothes?

All have	1
Majority have	2
Majority don't have	3

8.3 How frequently during the last year at least some household members had to live with clothes received as donation such as *zakat* or the like?

Most of the time	3
Now and then	2
Not at all	1

8.4 What proportion of the household members (walking children and above) has sandals/shoes?

Most of them	1
Some of them	2
None of them	3

Name of the interviewer: _____ Date of interview: _____

FORM 3

Data entry child ID no: [ ]

SRQ-20

The next questions are related to other common problems that may have bothered you in the **past 30 days……**

	Yes	No
1. Have you lost interest in things **since having this child**?		
2. Do you feel tired all the time?		
3. Do you find it difficult to enjoy your daily activities?		
4. Do you find it difficult to make decisions?		
5. Is it difficult to have clear thinking?		
6. Is it more difficult to do your daily work?		
7. Do you feel that you are you unable to play a useful part in life?		
8. Do you feel unhappy?		
9. Do you feel that you are a worthless person?		
(10. Has the thought of ending your life been on your mind?)		
11. Do you cry more than usual?		
(12. Are you easily tired?)		
13. Does your stomach feel bad?		
14. Are you suffering from headaches?		
15. Do you lack appetite?		
16. Have you been lacking in sleep?		
17. Are you easily frightened?		
18. Do your hands shake?		
19. Do you feel tension?		
20. Are you having difficulty digesting food?		

FORM 4

Data entry child ID no: ____

MEDICAL HISTORY & examination

201 Date: _____

202 **Interviewee:** 1. Mother 2. Maternal Gimother 3. Paternal Gimother 4. Father
5. Other:_____

203 **Birth history:**

204 **Past medical history:**

1. Has the child ever been admitted to hospital? 1.Y | 2.N

2. If yes, What for? 1. _____ 1.1 How many times + periods of stay? _____

2. _____ 2.2 _____

3. _____ 3.3 _____

205 **Overall Diagnosis:** 1. Cerebral Palsy 2. Progressive Disease 3. Metabolic Disorder

206 **CP Diagnosis:**

1. **Type** 1.Spastic 2.Hypotonic 3.Athetoid 4.Mixed 5.Don't know

2. **Involvement** 1.Heml 2.Diplegic 3.Quadraplegic

(To be completed by researcher : 3. **Severity level** (for age) 1. I 2. II 3. III 4. IV 5. V)

207 **Current medical state:**

1. Is the child sick now? 1.Y | 2.N

2. If yes, What is the matter?

3. Has the child been ill in the past two weeks? 1.Y | 2.N

4. What was the matter?

1

FORM 4

208 **Chest status:**

History

1. Asthma (wet or dry cough) 1.Y 2.N
2. Recurrent chest infections 1.Y 2.N

208.1.1 1.Daily 2.Wkly 3.Mthly 4.2-3mthly 5.6mthly 6.Yrly

208.2.1 1.Daily 2.Wkly 3.Mthly 4.2-3mthly 5.6mthly 6.Yrly

Clinical examination

3. Rattly, wet, noisy breathing 1.Y 2.N
4. Wheezy / crepitus breathing 1.Y 2.N
5. Chest structure abnormality (Deformity or intercostal recession) 1.Y 2.N

209 **Impairments / conditions:**

1. Postural deformity 1.Y 2.N
2. Tactile hypersensitivity 1.Y 2.N
3. Impaired hand function 1.Y 2.N
4. Dental problems 1.Y 2.N
5. Drooling 1.Y 2.N
6. Speech & language delay 1.Y 2.N
7. Suspected visual impairment 1.Y 2.N
8. Suspected hearing impairment 1.Y 2.N
9. Suspected cognitive impairment 1.Y 2.N
10. Behavioural problems 1.Y 2.N

11. Epilepsy 1.Y 2.N 11.1 Medication 1.Y 2.N Details:_____
12. Constipation 1.Y 2.N 12.1 Medication 1.Y 2.N Details:_____

210 **Other regular medication:**_____

211 **Mood: Ask mother** about child's mood **1.** Generally positive **2.** Neutral **3.** Generally negative

212 **Suspected gastro-oesophageal reflux (GOR):**

Ask mother;

1. Frequent spitting up, regurgitation, vomiting (during or after meals) ☐
2. Discomfort, agitation and sudden mood changes during/after meals ☐
3. Food refusal ☐
4. Increased congestion/breathing difficulties during feeds ☐
5. Sleep disturbance ☐
6. Sudden episodes of coughing/choking – not only during meals ☐

From chest assessment:

7. Breathing sounds wet all the time ☐
8. History of recurrent chest infection ☐
9. History of wheeze and asthma ☐

10. Conclusion: 1.Y 2.N Don't know

11. **Recommended Treatment for GOR:** 1.Position 2.Position & drugs 3.Drugs only 4. None

213. **Advised investigations / treatment :** Epilepsy ☐ GOR ☐ Constipation ☐

2

FORM 8

Data entry child ID no ☐

INITIAL FEEDING interview Date: _____

901.1 Was this child sick yesterday? 1. Y 2. No

901.2 If yes, what was the matter? _____

901.3 Has this child been sick at any other time in the past 2 weeks? 1. Y 2. N

901.4 If yes, what was the matter? _____ 901.5 For how many days? ☐

DIET

902. What did your child eat and drink yesterday?

FOOD	WHAT	QUANTITY	TEXTURE	UTENSIL
.1 Early morning				
.2 Mid morning				
.3 Midday				
.4 Afternoon				
.5 Evening/night				
DRINK				
.6 Over the whole day				

903.1 Are there other things your child typically eats & drinks but didn't eat yesterday? 1.Y 2.N 3.N/A

903.2 If yes, what things? _____

903.3 If sick yesterday: Did your child eat less because it was sick? 1.Y 2.N 3.N/A

904. In a typical day, how many times does this child eat? ☐

905.1 In a typical day, do/did the other children in your family of a similar age eat

Fewer meals in a day ☐ Same no. of meals ☐ More meals ☐ N/A ☐

905.1 If more meals, why? _____

906.1 What food does s/he like? _____

906.2 dislike? _____

907 Note textures reported: Thin liquid ☐ Thick liquid ☐ Puree ☐

Soft solid ☐ Easy-to-bite solid ☐ Chewy solid ☐ Mixed consistency / lumpy ☐ 1

308 Note utensils used: Hand ☐ Metal dessert spoon ☐ Chinese soup spoon ☐
Metal tsp ☐ Melamine tsp ☐ Feeder bottle ☐ Tall metal glass ☐ Short metal glass ☐
Tall plastic glass ☐ Short plastic glass ☐ Trainer cup ☐ Other_____ ☐

309 **What food does your child usually eat in a month?** (think of the past 3 months)

How frequently? **Every day? 2-3 x a week? 1 x a week? 1-2 x a month?**

No. of times (0, 1, 2 etc)

	Daily	Weekly	Monthly
1. Breast milk			
2. Cow's milk (alone)			
3. Suji (RP+milk+sugar)			
4. Suji (RP+milk+ghee+sug)			
(RP = rice powder) (ghee / oil = interchangeable)			
5. Suji (RP+ghee+sugar)			
6. Suji (RP+sugar alone)			
7. Kitchuri (own recipe) *			
8. Kitchuri (our recipe)			

	D	W	M
9.1 Normal rice			
9.2 Pulsu rice			
10. Potato			
11. Green leafy vegetables			
12. Other vegetables			
13. Dhal / pulses			
14. Fruits			
15. Banana			
16. Eggs			
17. Meat/poultry/fish M F			
18. Butter/cheese/yogurt			
19. Other:			

20.0 **Do you cook with extra oil?** Y N

20.1 **Is food availability for this child always** 1. Poor 2. Reasonable 3. Varies during the year ?

20.2 **If food availability for this child varies over the year, how has it been over the past 3 months?**

1. Poor 2. Reasonable 3. N/A

310 **What has the rest of the family been eating?**

	D	W	M
1. Normal rice			
1.2 Pulsu rice			
1.3 Kitchuri			
2. Potato			
3. Green leafy vegetables			
4. Other vegetables			
5. Dhal / pulses			
6. Fruits			
7. Banana			
8. Eggs			
9. Meat/poultry/ M F			
10. Butter/cheese/yogurt			
11. Other:			

2

FEEDING (Form 3) **Date:** **Interviewee:** **Child ID no:** ☐

311 **Which people feed this child?** 1.Mother ☐ 2. Maternal G/mother ☐ 3. Paternal G/mother ☐
4.Sibling ☐ 5.Other ☐

312 **Who is the main feeder?** 1.Mother ☐ 2. Maternal G/mother ☐ 3. Paternal G/mother ☐
4.Sibling ☐ 5. Other ☐ _____

313 **How much help does your child need with feeding?** 1. **You have to feed your child**
2. **Your child helps to feed itself**

314.1 **Do you know when your child is hungry?** 1.Y 2.N

314.2 If yes, **how? / what does your child do?**

314.3 **Do you feed your child** 1. At fixed times only 2. Fixed times & when hungry 3. Only when hungry 4. Other:

315.1 **Do you know when your child is ready for the next mouthful?** 1.Y 2.N

315.2 If yes, **how do you know / what does your child do?**

316.1 **Do you know when your child wants to stop?** 1.Y 2.N

316.2. If yes, **what does your child do?**

316.3 **Do you stop when your *child* wants to or when *you* want to?** 1. Child 2. Caregiver

317 **What do you do if your child refuses to eat?**

3

318 **What problems is your child having with FEEDING?** (ONLY prompt: "what else?")

319.1 **Do these problems bother you?** 1. Not very 2. A little 3. Somewhat 4. Very

319.2 **If so, in what way? What bothers you? How does it make you feel (overall + during feeding)?**

319.3 **How do you feel during mealtimes?** Eg Do you feel angry / frustrated / tired,...

320. **What <u>other</u> things does your child have difficulty with/is unable to do?** (Categorise the caregiver's answers. Don't give choices)

.1 Sitting balance	☐	.4 Talking	☐
.2 Head control	☐	.5 Independence in ADL	☐
.3 Walking	☐	.6 Other	☐

321. **Of all the problems (including feeding), which ones worry you the most?** (top 2-3)

.1 Sitting balance	☐	.4 Talking	☐	
.2 Head control	☐	.5 Independence in ADL	☐	
.3 Walking	☐	.6 Eating & drinking	☐	1. **Self-feeding** 2. **Chewing & swallowing**
		.7 Other	☐	

322. Does your child have any of the following problems? (Always, Sometimes or Never)

1.1 Do main meals take a long time? 1.A | 2.S | 3.N

1.2 How long? 1. <1/2 hr 2.1/2hr 3.1/2-1hr 4.1 hr 5.1-2hrs 6. >2hrs

2. Are you short of time/in a hurry to feed your child? 1.A | 2.S | 3.N

3.1 Does your child refuse to eat (when they are well)? 1.A | 2.S | 3.N

3.2 Does your child NOT respond to food? 1.A | 2.S | 3.N

4. Do you think your child eats enough?

5. Does your child spill a lot from mouth when eating? 1.A | 2.S | 3.N

6. Does your child cough or choke on food? 1.A | 2.S | 3.N

7. Does your child cough or choke on drink? 1.A | 2.S | 3.N

8. Does food come back up through your child's nose? 1.A | 2.S | 3.N

9. Does your child vomit during or after meals? 1.A | 2.S | 3.N

10. Does your child cry a lot during feeding? 1.A | 2.S | 3.N

11. Do you feed your child lying down? 1.A | 2.S | 3.N

12. Do you feed your child with its head back? 1.A | 2.S | 3.N

13.1 Do you ever need to force your child to eat, verbally? 1.A | 2.S | 3.N

13.2 Do you ever need to force your child to eat, physically? 1.A | 2.S | 3.N

14 . Is your child particular about what it eats? 1.Y 2.N

324.1 Have you ever had any previous advice from a hospital on FEEDING your child? 1.Y 2.N

324.2 If yes, Where from, when, and level of contact?

Where from	Which year	Frequency	Duration
Eg. CRP	2002	2 x monthly / 3 one-off visits / 14 day intensive	6 months / 14 days

324.3 What advice were you given?

5

324.4 Were you able to follow the advice? 1.All 2.Some 3.None 4.N/A

324.5 If not "All", what advice could you not follow and why?

Have you been to the Shishu Hospital or other centre for general advice on your child's disability? Y N

Details:

DESIRE / CAPACITY FOR CHANGE

325. Would you like help/advice from us regarding your child's feeding?		1. Y	2. N
326. What do you hope we can change?			
327. If our advice requires extra time to prepare your child's food – will this be a problem?	1. Y	2. N	3. Maybe
328. If our advice requires extra time to feed your child, will this be a problem?	1. Y	2. N	3. Maybe

LEVEL OF SUPPORT

329. Some husbands are sympathetic to the extra burden a disabled child places on the mother? Some are not. Is your husband sympathetic?	1. Y	2. N	3. N/A
330.1 Is your husband's family supportive in terms of the extra burden this child places on you?	1. Y	2. N	3. N/A
330.2 Is your own family supportive?	1. Y	2. N	3. Indiff
331. Is your community supportive?	1. Y	2. N	3. Indiff

FORM 7 Data entry child ID no:

MEALTIME OBSERVATION SCHEDULE

701 **Date:**
702 **Location:**
703 **Feeder:**
704.1 **Is the child sick today? Y N**
704.2 **If so, what is the matter?** _____
747.1 **At end ask: Was this a typical mealtime? Y N**
747.2 If not, why / in what way?

705 **What food & drink given:**
706 **Duration of meal:**
707.1 **Meal terminated by:** 1. Feeder 2. Researcher
707.2 **Reason:** 1. Food finished 2. Child wants to stop 3.Other:

CHILD AT REST			
708 Drooling:	1.N 2. A little 3.A lot (multiple)		
709.1 Mouth sitting open	1.N 2. A little 3.A lot (multiple)		
709.2 Tongue sitting forwards	1.N 2. A little 3.A lot (multiple)		
710 Breathing sounds wet / noisy. can hear wet sounds in throat:	1.N 2.Y 3.DK		
711 Sitting ability:	1. Can sit on floor independently	2. Can sit on floor with little / some support	3. Needs total support
712 Upper limb mobility:	1. Can bring things to mouth independently & at will	2. Can bring things to mouth with support	3. Unable to bring things to mouth with support

EATING - CHILD'S FEEDING BEHAVIOURS		√
713 **Oral behaviours**	1. Aversive behaviour to oral-tactile input	
	2. Absence of response to oral input	
	3. Excessive drooling / oral spillage	
	4. Ltd lip closure	
	5. Ltd jaw opening / stabilisation	
	6. Tongue pumping	
	7. Tongue thrust	
	8. Ltd lateralisation of tongue / jaw	
	9. Bite reflex / hypersensitivity	
	10. Spitting out	
	11. Pocketing	
	12. Other eg. signs of struggle/grimace	

Feeding pattern: Suckling > Munching > Chewing

061205 1

		Occas	Freq
714 **Pharyngeal / oesophageal signs**	1. Wet sounds in throat		
	2. Throat-clearing		
	3. Coughing		
	4. Gagging		
	5. Becoming breathless/noisy breathing		
	6. Face changing colour / tears in eyes		
	7. Distress signs during / after swallow		
	8. Nasal regurgitation		
	9. Oral regurgitation		
	10. Delayed or absent swallow		
	11. *Numerous attempts to swallow*		
	12. Other		

DRINKING - CHILD'S FEEDING BEHAVIOURS			√
715 **Oral behaviours**	1. Aversive behaviour to oral-tactile input		
	2. Absence of response to oral input		
	3. Excessive drooling / oral spillage		
	4. Ltd use of lips / lip closure		
	5. Ltd jaw opening / stabilisation		
	6. Tongue pumping or munching action		
	7. Tongue thrust		
	8. Bite reflex		
	9. Spitting out		
	10. Other		
715 **Pharyngeal / oesophageal signs**	1. Wet sounds in throat		
	2. Throat-clearing		
	3. Coughing		
	4. Gagging		
	5. Becoming breathless/noisy breathing		
	6. Face changing colour / tears in eyes		
	7. Distress signs during / after swallow		
	8. Nasal regurgitation		
	9. Oral regurgitation		
	10. Delayed or absent swallow		
	11. *Numerous attempts to swallow*		
	12. Other		

EATING & DRINKING - CHILD'S AFFECT	
741.1 **Mood** (multiple)	1. Content throughout 2. Partly content 3. Complaining / uncomfortable 4. Distressed
741.2 If answered 3 above, is it…. (multiple)	1. As food approaches 2. At other times – occasionally 3. At other times - sometimes 4. Most/all of the time 5. N/A
741.3 If answered 4 above, is it….(multiple)	1. As food approaches 2. At other times – occasionally 3. At other times - sometimes 4. Most/all of the time 5. N/A
742.1 **Awareness**	1. Aware of food 2. Unaware of food
742.2 If answered 2 above, is it….	1. Some of the time 2. All of the time 3. N/A

CARER'S INTERACTION behaviour						
Before meal						
743.1 **Prepares** child for feeding – verbal/ sense					1. Y	2. N
743.2 **Prepares** child for feeding – facial muscles					1. Y	2. N
During meal		1. **Never**	2. **Occasly**	3.**S/times**	4.**Mostly**	5. **Always**
744 **Proactiveness**	741.11 +ve verbal					
	741.12 physical					
	741.21 -ve verbal					
	741.22 physical					
745 **Responsiveness**	742.1 +ve					
	742.2 -ve					

Occasionally = once or twice during the session, Sometimes = 50% of the time, Mostly = 75+% of the time

746. **Feeder washed hands before feeding** 1. Y 2. N

747. **Use of our equipment** (multiple)

Seat	1. Y	2. N	3. N/A
Spoon	1. Y	2. N	3. N/A
Beaker	1. Y	2. N	3. N/A

EATING - FEEDING METHOD		
717 **Food consistency**	1. Thin liquid	
	2. Thick liquid (eg. normal suji)	
	3. Puree (eg. mashed veg + milk / cerelac / thick suji)	
	4. Soft solid (eg. Kitchuri)	
	5. Easy-to-bite solid (eg. papaya)	
	6. Chewy solid	
	7. Mixed consistency / lumpy (eg. watery curry with lumps)	
	8. Homogeneous	
720 **Support given for jaw / lip control**	1. No support	
	2. Support some of the time	
	3. Support all of the time	
721 **Support for self-feeding**	1. Child totally uninvolved in self-feeding	
	2. Child encouraged to be involved in self-feeding – few mthls	
	3. Child encouraged to be involved in self-feeding – > ½ meal	
722 **Seating**	1. Floor / bed	
	2. Lap – on chair / floor / bed	
	3. Special seat	
723 **Utensil used**	1. Hand	
	2. Metal dessert spoon	
	3. Chinese soup spoon	
	4. Metal teaspoon	
	5. Melamine/plastic teaspoon	
	6. Other:	
724 **Amount per mouthful**	1. Large fistful / dessert-spoonful	
	2. Full tsp	
	3. Half tsp or less	
	4. N/A (feeder bottle)	
728 **Management of spillage**	1. Scooping food back into mouth	
	2. Aggressive wiping of mouth	
	3. Gentle wiping / removal of spillage / dabbing around mouth	
	4. N/A	
729 **Management of any food remaining in the mouth**	1. Food not cleared between mouthfuls	
	2. Food cleared between mouthfuls	
	3. Food not cleared after eating	
	4. Food cleared after eating	
	5. N/A (feeder bottle)	

718 **Positioning – trunk and pelvis**	1. Fed lying down, head unsupported	
	2. Fed lying down, head supported	
	3. Fed reclined (breast-feeding position)	
	4. Sitting up/ semi-reclined and trunk flexed (front/side)	
	5. Sitting up/semi-reclined, trunk extended (front/side)	
	6. Sitting up/semi-reclined, trunk straight (front/side)	
	7. Other	
719 **Head position**	1. Head very extended	
	2. Head slightly extended	
	3. Head very flexed	
	4. Head slightly flexed	
	5. No flexion, no extension	
	6. Head in rotation (R or L)	
	7. Head in rotation (R or L) - probable ATNR	
	8. Head facing front	
	9. Head midline	
	10. Head off midline	

725 **Pacing**	1. Continuous (with / without breaks) (feeder bottle)	
	2. Fast – 1 mouthful per 1-3 seconds	
	3. Medium – 1 mouthful per 5-10 seconds	
	4. Slow – 1 mouthful per 10+ seconds	
726 **Delivery to mouth - angle**	1. Food given from above / utensil tilted upwards	
	2. Food given straight (90 degrees)	
	3. Food given from side	
	4. Food given from front	
	5. Spoon facing forwards	
	6. Spoon sideways on	
	7. N/A	
	8. Spoon withdrawn straight	
	9. Spoon withdrawn over top teeth/lip	
	10. N/A	
727 **Delivery to mouth - speed**	1. Food pushed in quickly	
	2. Food delivered at controlled rate	

DRINKING - FEEDING METHOD		
730 **Consistency**	1. Thin liquid	
	2. Thick liquid	

737 **Amount per mouthful**	1. Whole mouthful / spoonful	
	2. Small mouthful / spoonful	
	3. N/A (feeder bottle)	

733 **Support for jaw / lip control**	1. No support	
	2. Support some of the time	
	3. Support all of the time	
734 **Support for self-feeding**	1. Child totally uninvolved in self-feeding	
	2. Child encouraged to be involved in self-feeding – few mthfls	
	3. Child be involved in self-feedng – >1/2 meal	
735 **Seating**	1. Floor / bed	
	2. In / on lap – on chair / floor / bed	
	3. Special seat	
736 **Utensil used**	1. Bottle / "feeder"	
	2. Metal dessert spoon	
	3. Metal teaspoon	
	4. Melamine / plastic teaspoon	
	5. Tall metal glass	
	6. Short metal glass	
	7. Tall plastic glass	
	8. Short plastic glass	
	9. Double-handed trainer cup with lid	
	10. Double-handed trainer cup without lid	
	11. Other:	

740.1 **Mixing drinks with food**			Y	N
740.2 **Cup kept well filled**		Y	N	N/A

6

731 **Positioning - trunk & pelvis**	1. Fed lying down, head unsupported	
	2. Fed lying down, head supported	
	3. Fed reclined (breast-feeding position)	
	4. Sitting up/ semi-reclined and trunk flexed (front/side)	
	5. Sitting up/semi-reclined, trunk extended (front/side)	
	6. Sitting up/semi-reclined, trunk straight (front/side)	
	7. Other:	
732 **Head position**	1. Head very extended	
	2. Head slightly extended	
	3. Head very flexed	
	4. Head slightly flexed	
	5. No flexion, no extension	
	6. Head in rotation (R or L)	
	7. Head in rotation (R or L) - probable ATNR	
	8. Head facing forwards	
	9. Head midline	
	10. Head off midline	

738 **Pacing**	1. Continuous feeding without breaks	
	2. Continuous feeding with breaks	
	3. Fast with breaks between (1 mouthful per 1-3 secs)	
	4. Medium breaks between mouthfuls (1 mthfl per 5-10 secs)	
	5. Slow – 1 mouthful per 10+ secs	
739 **Delivery to mouth**	1. Given from above / utensil tilted upwards	
	2. Given from straight	
	3. Given from side	
	4. Given from front	
	5. Spoon facing forwards	
	6. Spoon sideways on	
	7. **N/A**	
	8. Spoon withdrawn straight	
	9. Spoon withdrawn over top teeth/lip	
	10. **N/A**	

Form 8 Data entry child ID no:

801. **Date:**

TRAINING NEEDS SUMMARY

802. **Child**

1. ↑ Nutrition
2. ↑ Hydration
3. ↓ Risk aspiration
4. ↓ Discomfort / distress
5. ↓ vomiting
6. ↑Involvement in self-feeding
7. ↓ spillage
8. ↑ Maturity of feeding pttn Suckling > munching
   Munching > chewing

803. **Caregiver**

1. ↑ +ve Responsiveness
2. ↑ +ve Proactiveness
3. ↓ -ve Proactive

TARGET AREAS

804. Target area identified		Specific instructions	Advised during 1:1 √	2nd Bsl Complce 0,1,2	1st RVW Complce 0,1,2	2nd RVW Complce 0,1,2
GENERAL						
1	DIET + quantity + frequency					
2	TEXTURE / CONSISTENCY					
3	Desensitization/ ORAL EXERCISES					
FEEDING METHOD - FOOD						
4	VERBAL / SENSORY PREPARATION					
5.1	POSITION					
5.2	SPPT TO LIPS/JAW					
6	SPPT FOR SELF-FEEDING					
7	UTENSIL					
8.1	AMOUNT					
8.2	PACING					
8.3	DELIVERY					
9	SPILLAGE / FOOD TO CLEAR					

FEEDING METHOD – DRINK						
10	QUANTITY					
11	TEXTURE / CONSISTENCY					
12	SENSORY PREPARATION					
13.1	POSITION					
13.2	SPPT TO LIPS/JAW					
14	SPPT FOR SELF-FEEDING					
15	UTENSIL					
16.1	AMT					
16.2	PACING					
16.3	DELIVERY					
17	SPILLAGE					
18	MIXING WITH FOOD					

INTERACTION						
19.1	Proactive	+ve				
		-ve				
19.2	Responsive	+ve				

Additional advice:					

Compliance scores 0 = No change
1 - Partial change
2 = 'Goal' achieved

FORM 8a Date:

GOAL REVIEW - Caregiver's report

Goal no.	Unprompted recall		Prompted recall		Not recalled / recalled incorrectly		Achieved		Not achieved	Reason for partial / non achievement
	Fully	Partial	Fully	Partial			Fully	Partly		

FORM 9

Data entry child ID no: ☐

POST ADVICE INTERVIEW

Date of visit:_____

Chair in use 1.Y 2.N Advice sheets hanging up 1.Y 2.N

GENERAL

How are things? Have there been any changes in your domestic situation since we first came to visit you?

EMOTIONAL STATE

Since we asked you questions about how you feel, has anything changed? Do you feel less or more unhappy / upset/ worried? 1. Better 2. Same 3. Worse

HEALTH

Is your child sick now? 1.Y | 2.N

If yes, what is the matter? _____

Has the child been ill in the past two weeks? 1.Y | 2.N

If Y, what was the matter? _____

For how many days? ☐

Has your child been sick (with anything else) since we last saw you? 1.Y | 2.N

If Y, What was the matter? _____ How many times? ☐

_____ ☐

_____ ☐

_____ ☐

Has this child had problems with constipation? 1.Y | 2.N

If Y, have they been 1. Less than before 2. Same 3. Worse 4. N/A

1

Check GOR symptoms if relevant (see previous Ax) **- Problems still?** 1. Y 2. N 3. Maybe 4. N/A

Since we last saw you, how would you describe how this child's behaviour/mood has been?	1.Generally positive	2.Neutral	3.Generally negative

FEEDING ASSESSMENT REVIEW

OK – so let's see what's changed. I'm going to ask you some of the same questions as on our first visit.

How much help does your child need with feeding? 1. You have to feed your child
2. Your child helps to feed itself

If 2. is it: Snacks ☐ 1. A few mthfls 2. Half of the time 3. Most/all of the time 4. N/A

Main meals ☐ 1. A few mthfls 2. Half of the time 3. Most/all of the time 4. N/A

Do you know when your child is hungry? **1.Y 2.N**

If yes, **how? / what does your child do?**

Do you feed your child 1. At fixed times only 2. Fixed times & when hungry 3. Only when hungry 4. Other:

Do you know when your child is ready for the next mouthful? 1.Y 2.N

If yes, **how do you know / what does your child do?**

Do you know when your child wants to stop? 1.Y 2.N

If yes, **what does your child do?**

Do you stop when your *child* wants to or when *you* want to? 1. Child 2. Caregiver 3. Both

What do you do if your child refuses to eat?

What problems is your child now having with EATING & DRINKING? (ONLY prompt: "what else?")

How much do these problems bother you? 1. Not really 2. A little 3. Somewhat 4. Very 5. N/A

If bothered: Why, in what way?

How do you feel during mealtimes, when you're feeding your child? (Good, annoyed, angry, tired – Occas, Stimes, mostly)

Does your child still have any of the following problems? (nearly) Always, Sometimes or (nearly) Never)

1.1 **Do <u>main</u> meals take a long time?** | 1.**A** | 2.**S** | 3.**N** |

1.2 **How long?** 1. **<1/2 hr** 2.**1/2hr** 3.**1/2-1hr** 4.**1 hr** 5.**1-2hrs** 6. **>2hrs**

2. **Are you short of time/in a hurry to feed your child?** | 1.**A** | 2.**S** | 3.**N** |

3.1 **Does your child refuse to eat (when they are well)?** | 1.**A** | 2.**S** | 3.**N** |

3.2 **Does your child NOT respond to food?** | 1.**A** | 2.**S** | 3.**N** |

4. **Do you think your child eats enough?** | 1.**A** | 2.**S** | 3.**N** |

5. **Does your child spill a lot from mouth when eating?** | 1.**A** | 2.**S** | 3.**N** |

3

6. Does your child cough or choke on food? 1.A | 2.S | 3.N

7. Does your child cough or choke on drink? 1.A | 2.S | 3.N

8. Does food come back up through your child's nose? 1.A | 2.S | 3.N

9. Does your child vomit during or after meals? 1.A | 2.S | 3.N

10. Does your child cry a lot during feeding? 1.A | 2.S | 3.N

11.1 Do you feed your child lying down? 1.A | 2.S | 3.N

12. Do you feed your child with its head back? 1.A | 2.S | 3.N

13.1 Do you ever need to force your child to eat, verbally? 1.A | 2.S | 3.N

13.2 Do you ever need to force your child to eat, physically? 1.A | 2.S | 3.N

14 . Is your child particular about what it eats? 1.Y 2.N

HYGIENE awareness

How many times do you/others cook for the family in a day?				
If you're preparing (> 5 mins) additional food for this child, how many times do you do this in a day?				
How long do you leave food out (of the fridge) after cooking, before your child eats it?	1. 1/2 day	2. whole day	3. day + night	4.N/A
How many times do you reheat the food this child eats?				
Do your family clean their teeth daily?	1. Always	2. Sometimes	2. Never	
Do you clean this child's teeth daily?	1. Always	2. Sometimes	2. Never	
How?				

Do you do any face & mouth exercises to help your child eat? 1. Y 2. N

If yes: Which ones? (Don't prompt)

Pre-meal facial preparation	☐	Every meal? Y N
Chewing	☐	Every day? Y N
Tongue	☐	Every day? Y N
Lips	☐	Every day? Y N
Other (describe)	☐	Every day? Y N

N/A ☐

DIET

What did your child eat and drink yesterday?

FOOD	WHAT	QUANTITY	TEXTURE	UTENSIL
.1 Early morning				
.2 Mid morning				
.3 Midday				
.4 Afternoon				
.5 Evening/night				
DRINK				
.6 Over the whole day				

Are there other things your child typically eats & drinks but didn't eat yesterday? 1.Y 2.N 3.N/A

If yes, what things? _____

If sick yesterday: Did your child eat less because it was sick? 1.Y 2.N 3.N/A

In a typical day, how many times does this child eat? ☐

What food does s/he like? _____

dislike? _____

Note textures reported: Thin liquid ☐ Thick liquid ☐ Puree ☐

Soft solid ☐ Easy-to-bite solid ☐ Chewy solid ☐ Mixed consistency / lumpy ☐

Note utensils used: Hand ☐ Metal dessert spoon ☐ Chinese soup spoon ☐

Metal tsp ☐ Melamine tsp ☐ Feeder bottle ☐ Tall metal glass ☐ Short metal glass ☐

Tall plastic glass ☐ Short plastic glass ☐ Trainer cup ☐ Other_____ ☐

5

What food does your child usually eat in a month? (think of the past 3 months)

	Daily	Weekly	Monthly
1. Breast milk			
2. Cow's milk (besides in suji)			
3. Suji (RP/WP+milk+sugar)			
4. Suji (RP/WP+milk+oil+sug)			
(RP = rice powder) (WP= wheat powder)			

	D	W	M
5. Suji (RP/WP+oil+sugar)			
6. Suji (RP/WP+sugar alone)			
7. Kitchuri (own recipe) *			
8. Kitchuri (our recipe)			

	D	W	M
9.1 Normal rice			
9.2 Pulau rice			
10. Potato			
11. Green leafy vegetables			
12. Other vegetables			
13. Dhal / pulses			

	D	W	M
14. Fruits			
15. Banana			
16. Eggs			
17. Meat/poultry/fish M F			
18. Butter/cheese/yogurt			
19. Other:			

When cooking for this child, do you use extra oil? 1.Y 2.N

If Y: **Is this a new thing – since seeing us?** 1.Y 2.N 3. N/A

Is food availability for <u>this child</u> always 1. Poor 2. Reasonable 3. Varies during the year

If answer 3: **How has it been over the past 2 months?** 1. Poor 2. Reasonable 3. N/A

Has the family food changed over the past 2 months? 1.**Y** 2.**N**

If yes, in what way? _____

How much do you use the chair we gave you?

(i) At mealtimes: 1. Y 2. N If Y, **every day?** 1. Y 2. N 3. N/A If Y, **How many meals per day?** ☐

(ii) At other times: 1. Y 2. N If Y, **every day?** 1. Y 2. N 3. N/A If Y, **How many times per day?** ☐

For how long each time ☐ **Total hours in the day** 1. 0 2. 0-1 3. 1-3 4. 3+

How useful have you found the diet sheet we gave you? 1. Not 2. A little 3. Somewhat 4. Very 5. N/A

How useful have you found the blue instruction sheet? 1. Not 2. A little 3. Somewhat 4. Very

OBSERVE FEEDING & NOTE COMPLIANCE – Observed & Reported

6

TEST OF KNOWLEDGE I want to ask you some general questions about food preparation and feeding:

Diet

1. **What is the most important cooking ingredient for giving your child energy ?**
   1. Oil
   2.Other

2. **How many times should you feed your child in a day?**
   1. Five or six
   2.Other:

3. **How much water should your child drink every day?**
   1. Five glasses
   2.Other:

Positioning & support for self-feeding

4. **In what position should you never feed your child?**
   1.Lying down / head back
   2.Other:

5. **Why?**
   1.Risks to chest
   2.Other:

6. **Why should you encourage your child to try to feed itself?**
   1.To encourage independence
   2. To make it want to eat
   3. Other:

Food consistency

7. **What food consistency should you avoid?**
   1.Mixed / very runny
   2.Other:

Responsive feeding

8. **How do you know what speed to feed your child and how much to put in his/her mouth?**
   1.Watch child's behaviour (or answer suggesting this)
   2.Other

9. **How should you encourage your child to eat?**
   1.Gentle and patient talking
   2. Other:

10. **Why should you not force your child to eat or drink?**
    1. It can be harmful to their chest
    2. It is cruel / unkind
    3. Other:

Hygiene

11. **Why should you only reheat food once?**
    1.Loses nutritional value
    2.Other:

12. **Why are worms not good for your child's health?**
    1.Child can't absorb goodness from food
    2.Other

TOTAL SCORE ☐

7

REVIEW TRAINING NEEDS SUMMARY & reiterate / change.
Overall, how useful has the information we've given you been?

1. Not	2. A little	3. Some-what	4. Very

What changes, if any, do you see in your child? (Ability to eat, ability to drink, other)

Do you see any changes in yourself? Do you feel differently about your child's feeding problems / when you feed your child? (Eg. more confident, more optimistic)

What, if anything, would you like to change/improve further with regard to your child's eating and drinking?

GO THROUGH PREVIOUS TRAINING SHEET & REVIEW ADVICE

Do you have any questions?

8

FORM 10

Data entry child ID no: ☐

POST TRAINING INTERVIEW 1

Date of visit:_____

Chair in use 1.Y 2.N Advice sheets hanging up 1.Y 2.N

GENERAL

How are things? Have there been any changes in your domestic situation since we first came to visit you?

HEALTH

Is your child sick now? 1.Y | 2.N

If yes, what is the matter? ☐

Has the child been ill in the past two weeks? 1.Y | 2.N

If Y, what was the matter? ☐

For how many days? ☐

Has your child been sick (with anything else) since starting the groups? 1.Y | 2.N

If Y, What was the matter? _____ How many times? ☐

_____ ☐

_____ ☐

_____ ☐

Since starting the groups:

Has this child had problems with constipation? 1.Y | 2.N

If Y, have they been 1. Less than before 2. Same 3. Worse 4. N/A

Since starting the groups, how would you describe how this child's behaviour/mood has been? | 1.Generally positive | 2.Neutral | 3.Generally negative |

1

If GOR suspected previously:

Ask mother;

1. Frequent spitting up, regurgitation, vomiting (during or after meals) ☐
2. Discomfort, agitation and sudden mood changes during/after meals ☐
3. Food refusal ☐
4. Increased congestion/breathing difficulties during feeds ☐
5. Sleep disturbance (* see answer above) ☐
6. Sudden episodes of coughing/choking – not only during meals ☐

From chest assessment: ☐

7. Breathing sounds wet all the time ☐
8. Continued chest infections

Conclusion: 1. Possible GOR 2. GOR resolved 3. N/A

FEEDING ASSESSMENT REVIEW

OK – so let's see what's changed. I'm going to ask you some of the same questions as on our first visit.

How much help does your child need with feeding? 1. You have to feed your child
2. Your child helps to feed itself

If 2. is it: 1. Occasionally 2. Half of the time 3. Most/all of the time

Do you know when your child is hungry? 1.Y 2.N

If yes, **how? / what does your child do?**

Do you feed your child 1. At fixed times only 2. Fixed times & when hungry 3. Only when hungry 4. Other:

Do you know when your child is ready for the next mouthful? 1.Y 2.N

If yes, **how do you know / what does your child do?**

Do you know when your child wants to stop? 1.Y 2.N

If yes, **what does your child do?**

Do you stop when your *child* wants to or when *you* want to? 1. Child 2. Caregiver

What do you do if your child refuses to eat?

What problems is your child now having with FEEDING? (ONLY prompt: "what else?")

How much do these problems bother you? 1. Not really 2. A little 3. Somewhat 4. Very 5. N/A

If bothered: Why, in what way?

How much do the fact that your child still does not eat like other children bother you? 1. Not really 2. A little 3. Somewhat 3. Very

If bothered: **Why, in what way?**

How do you feel during mealtimes, when you're feeding your child?

3

What other things does your child have difficulty with/is unable to do? (Categorise the caregiver's answers. Don't give choices)

.1 Sitting balance	☐	.4 Talking	☐
.2 Head control	☐	.5 Independence in ADL	☐
.3 Walking	☐	.6 Other	☐

Of all the problems (including feeding), which ones worry you the most? (top 2-3)

.1 Sitting balance	☐	.5 Independence in ADL	☐	
.2 Head control	☐	.6 Feeding	☐	1. **Self-feeding** 2. **Chewing & swallowing**
3 Walking	☐	.7 Other	☐	
.4 Talking	☐			

LEVEL OF SUPPORT

Is your husband sympathetic to the extra burden a disabled child places on you?	1. Y	2. N	3. N/A
Is your husband's family supportive in terms of the extra burden this child places on you?	1. Y	2. N	3. N/A
Is your own family supportive?	1. Y	2. N	
Is your community supportive?	1. Y	2. N	

Back to feeding;
Does your child still have any of the following problems? (nearly) Always, Sometimes or (nearly) Never)

1.1 **Do main meals take a long time?** | 1.**A** | 2.**S** | 3.**N** |

1.2 **How long?** 1. **<1/2 hr** 2.**1/2hr** 3.**1/2-1hr** 4.**1 hr** 5.**1-2hrs** 6. **>2hrs**

2. **Are you short of time/in a hurry to feed your child?**	1.**A**	2.**S**	3.**N**
3.1 **Does your child refuse to eat (when they are well)?**	1.**A**	2.**S**	3.**N**
3.2 **Does your child NOT respond to food?**	1.**A**	2.**S**	3.**N**
4. **Do you think your child eats enough?**	1.**A**	2.**S**	3.**N**
5. **Does your child spill a lot from mouth when eating?**	1.**A**	2.**S**	3.**N**
6. **Does your child cough or choke on food?**	1.**A**	2.**S**	3.**N**
7. **Does your child cough or choke on drink?**	1.**A**	2.**S**	3.**N**

8. **Does food come back up through your child's nose?** | 1.**A** | 2.**S** | 3.**N** |

9. **Does your child vomit during or after meals?** | 1.**A** | 2.**S** | 3.**N** |

10. **Does your child cry a lot during feeding?** | 1.**A** | 2.**S** | 3.**N** |

11.1 **Do you feed your child lying down?** | 1.**A** | 2.**S** | 3.**N** |

12. **Do you feed your child with its head back?** | 1.**A** | 2.**S** | 3.**N** |

13.1 **Do you ever need to force your child to eat, verbally?** | 1.**A** | 2.**S** | 3.**N** |

13.2 **Do you ever need to force your child to eat, physically?** | 1.**A** | 2.**S** | 3.**N** |

14 . **Is your child particular about what it eats?** 1.Y 2.N

HYGIENE awareness

How many times do you/others cook for the family in a day?				
If you're preparing (> 5 mins) additional food for this child, how many times do you do this in a day?				
How long do you leave food out (of the fridge) after cooking, before your child eats it?	1. 1/2 day	2. whole day	3. day + night	4.N/A
How many times do you reheat the food this child eats?				
Do your family clean their teeth daily?	1. Always	2. Sometimes	2. Never	
Do you clean this child's teeth daily?	1. Always	2. Sometimes	2. Never	
How?				

Are you doing the face & mouth exercises we taught you? 1. Y 2. N 3. N/A

If yes: **Which ones?** (Don't prompt) **Facial preparation** ☐ **When / How often** _____

Chewing ☐ _____

Tongue ☐ _____

Lips ☐ _____

N/A

What food does your child usually eat in a month? (think of the past 3 months)

	Daily	Weekly	Monthly
1. Breast milk			
2. Cow's milk (alone)			
3. Suji (RP+milk+sugar)			
4. Suji (RP+milk+ghee+sug)			
(RP = rice powder) (ghee / oil = interchangeable)			

	D	W	M
5. Suji (RP+ghee+sugar)			
6. Suji (RP+sugar alone)			
7. Kitchuri (own recipe) *			
8. Kitchuri (our recipe)			

	D	W	M
9.1 Normal rice			
9.2 Pulau rice			
10. Potato			
11. Green leafy vegetables			
12. Other vegetables			
13. Dhal / pulses			

	D	W	M
14. Fruits			
15. Banana			
16. Eggs			
17. Meat/poultry/fish M F			
18. Butter/cheese/yogurt			
19. Other:			

When cooking for this child, do you use extra oil? **1.**Y 2.N

If Y: **Is this a new thing – since receiving the training?** **1.**Y 2.N

Is food availability for <u>this child</u> always 1. Poor 2. Reasonable 3. Varies during the year

If answer 3: **How has it been over the past 3 months?** **1.** Poor **2.** Reasonable **3.** N/A

Has the family food changed over the past 3 months? 1.**Y** **2.N**

If yes, in what way? _____

Have you been able to do all the things we taught you to do in the training?

1.None	2.Some	3.Most	4. All

What were you able to do?

7

DIET

What did your child eat and drink yesterday?

FOOD	WHAT	QUANTITY	TEXTURE	UTENSIL
.1 Early morning				
.2 Mid morning				
.3 Midday				
.4 Afternoon				
.5 Evening/night				
DRINK				
.6 Over the whole day				

Are there other things your child typically eats & drinks but didn't eat yesterday? 1.Y 2.N 3.N/A

If yes, **what things?** _____

If sick yesterday: **Did your child eat less because it was sick?** 1.Y 2.N 3.N/A

In a typical day, how many times does this child eat? ☐

In a typical day, do/did the other children in your family of a similar age eat

Fewer meals in a day ☐ Same no. of meals ☐ More meals ☐ N/A ☐

If different, why? _____

What food does s/he like? _____

dislike? _____

Note textures reported: Thin liquid ☐ Thick liquid ☐ Puree ☐

Soft solid ☐ Easy-to-bite solid ☐ Chewy solid ☐ Mixed consistency / lumpy ☐

Note utensils used: Hand ☐ Metal dessert spoon ☐ Chinese soup spoon ☐

Metal tsp ☐ Melamine tsp ☐ Feeder bottle ☐ Tall metal glass ☐ Short metal glass ☐

Tall plastic glass ☐ Short plastic glass ☐ Trainer cup ☐ Other_____ ☐

6

What were you not able to do, and why?

How much do you use the chair we gave you?

(i) At mealtimes: 1. Y 2. N If Y, **how many meals** ☐

(ii) At other times: 1. Y 2. N If Y, **how many times per day** ☐ **and for how long each time** ☐

Total hours in the day ☐

TEST OF KNOWLEDGE

I want to ask you some questions about the things you learnt in the training. *(NB. No prompts)*

Diet

1. **What is the most important cooking ingredient for giving your child energy ?**
   1. Oil
   2.Other

2. **How many times should you feed your child in a day?**
   1. Five or six
   2.Other:

3. **How much water should your child drink every day?**
   1. Five glasses
   2.Other:

Positioning & support for self-feeding

4. **In what position should you never feed your child?**
   1.Lying down / head back
   2.Other:

5. **Why?**
   1.Risks to chest
   2.Other:

6. **Why should you encourage your child to try to feed itself?**
   1.To encourage independence
   2. To make it want to eat
   3. Other:

8

Food consistency

7. **What food consistency should you avoid?**

1.Mixed / very runny
2.Other:

Responsive feeding

8. **How do you know what speed to feed your child and how much to put in his/her mouth?**

1.Watch child's behaviour (or answer suggesting this)
2.Other

9. **How should you encourage your child to eat?**

1.Gentle and patient talking
2. Other:

10. **Why should you not force your child to eat or drink?**

1. It can be harmful to their chest
2. It is cruel / unkind
3. Other:

Hygiene

11. **Why should you only reheat food once?**

1.Loses nutritional value
2.Other:

12. **Why are worms not good for your child's health?**

1.Child can't absorb goodness from food
2.Other

Congratulate and remind of correct answers where necessary

TOTAL SCORE ☐

FEEDBACK ON PROGRAMME

How useful were the following aspects of the training programme?

	1. **Not very**	2. **Quite**	3. **Very**	4. **N/A**
1st home visit				
1st part of group sessions – Feedback & Teaching				
2nd part of group sessions – Feeding				
Video drama				
If **Very**, why?				
Spoon & cup **S C**				
Advice sheets **Y B**				
Chair				

9

Overall, do you think the training programme was useful/are you satisfied?

1. Not very	2. Some-what	3. Very

In what way? (What did you like best about it?)

What changes, if any, do you see in yourself? (**Do** anything differently? **Feel** any different? Eg. more confident, more optimistic)

What changes, if any, do you see in your child?

Was your family supportive of you attending the groups? 1. Not very 2. Quite 3.Very

Have you noticed any changes in your family's behaviour towards you or your child since you have been attending the groups? 1. Y 2. N

If Y, in what way? (eg. feed child differently now, take more notice of child...)

10

Of all the changes, what changes are you happiest about?

What, if anything, would you like to change/improve further with regard to your child's eating and drinking?

Is there anything else you want to tell us or ask us about the training programme?

FORM 11

Data entry child ID no:

POST TRAINING INTERVIEW 2

Date of visit:_____

Chair in use 1.Y 2.N Advice sheets hanging up 1.Y 2.N

GENERAL

How are things? Have there been any changes in your domestic situation since we first came to visit you?

EMOTIONAL STATE

Since we asked you questions about how you feel, has anything changed? Do you feel less or more unhappy / upset/ worried? 1. Better 2. Same 3. Worse

HEALTH

Is your child sick now? 1.Y 2.N

If yes, what is the matter? _____

Has the child been ill in the past two weeks? 1.Y 2.N

If Y, what was the matter? _____

For how many days? ☐

Has your child been sick (with anything else) since we last saw you? 1.Y 2.N

If Y, What was the matter? _____ How many times? ☐

_____ ☐

_____ ☐

_____ ☐

Has this child had problems with constipation? 1.Y 2.N

If Y, have they been 1. Less than before 2. Same 3. Worse 4. N/A

Check GOR symptoms if relevant (see previous Ax) - Problems still? 1. Y 2. N 3. Maybe 4. N/A

Since we last saw you, how has this child's behaviour/mood has been? 1.Generally positive | 2.Neutral | 3.Generally negative

1

Of all the problems your child has (eg…….including feeding), which ones worry you the most? (top 2-3)

.1 Sitting balance ☐ .5 Independence in ADL ☐

.2 Head control ☐ .6 Feeding ☐ 1. **Self-feeding** 2. **Chewing & swallowing**

3 Walking ☐ .7 Other ☐

.4 Talking ☐

FEEDING ASSESSMENT REVIEW

OK – so let's see what's changed. I'm going to ask you some of the same questions as before.

How much help does your child need with feeding? 1. You have to feed your child

2. Your child helps to feed itself

If 2. is it: Snacks ☐ **1.** A few mthfls **2.** Half of the time **3.** Most/all of the time **4.** N/A

Main meals ☐ **1.** A few mthfls **2.** Half of the time **3.** Most/all of the time **4.** N/A

Do you feed your child 1. At fixed times only 2. Fixed times & when hungry 3. Only when hungry 4. Other:

Do you stop when your *child* wants to or when *you* want to? 1. Child 2. Caregiver 3. Both

What do you do if your child refuses to eat?

What problems is your child now having with EATING & DRINKING? (ONLY prompt: "what else?")

Do you feel bothered about your child's eating and drinking? 1. **No** 2. **A little** 3. Somewhat 4. Very

2

How do you feel during mealtimes, when you're feeding your child? (Good, annoyed, angry, tired – Occas, Stimes, mostly)

Does your child still have any of the following problems? (nearly) Always, Sometimes or (nearly) Never)

Go back through ones marked A or S:

1.1 Do main meals take a long time? 1.A 2.S 3.N

1.2 How long? 1. <1/2 hr 2.1/2hr 3.1/2-1hr 4.1 hr 5.1-2hrs 6. >2hrs

2. Are you short of time/in a hurry to feed your child? 1.A 2.S 3.N

3.1 Does your child refuse to eat (when they are well)? 1.A 2.S 3.N

3.2 Does your child NOT respond to food? 1.A 2.S 3.N

4. Do you think your child eats enough? 1.A 2.S 3.N

5. Does your child spill a lot from mouth when eating? 1.A 2.S 3.N

6. Does your child cough or choke on food? 1.A 2.S 3.N

7. Does your child cough or choke on drink? 1.A 2.S 3.N

8. Does food come back up through your child's nose? 1.A 2.S 3.N

9. Does your child vomit during or after meals? 1.A 2.S 3.N

10. Does your child cry a lot during feeding? 1.A 2.S 3.N

11.1 Do you feed your child lying down? 1.A 2.S 3.N

12. Do you feed your child with its head back? 1.A 2.S 3.N

13.1 Do you ever need to force your child to eat, verbally? 1.A 2.S 3.N

1.A 2.S 3.N

3

13.2 Do you ever need to force your child to eat, physically?

14 . Is your child particular about what it eats? 1.Y 2.N

HYGIENE awareness

How many times do you/others cook for the family in a day?				
If you're preparing (> 5 mins) additional food for this child, how many times do you do this in a day?				
How long do you leave food out (of the fridge) after cooking, before your child eats it?	1. 1/2 day	2. whole day	3. day + night	4.N/A
How many times do you reheat the food this child eats?				
Do your family clean their teeth daily?	1. Always	2. Sometimes	2. Never	
Do you clean this child's teeth daily?	1. Always	2. Sometimes	2. Never	
How?				

Do you do any face & mouth exercises to help your child eat? 1. Y 2. N

If yes: Which ones? (Don't prompt)

Pre-meal facial preparation	☐	Every meal? Y N
Chewing	☐	Every day? Y N
Tongue	☐	Every day? Y N
Lips	☐	Every day? Y N
Other (describe)	☐	Every day? Y N

N/A ☐

How much do you use the chair we gave you?

(i) At mealtimes: 1. Y 2. N If Y, every day? 1. Y 2. N 3. N/A If Y, How many meals per day? ☐

(ii) At other times: 1. Y 2. N If Y, every day? 1. Y 2. N 3. N/A If Y, How many times per day? ☐

For how long each time ☐ Total hours in the day 1. 0 2. 0-1 3. 1-3 4. 3+

What changes, if any, do you see in your child since we last saw you? (Ability to eat, ability to drink, other)

What changes, if any, are there in the way you feed your child since you have met us?

How do you feel now about feeding your child? (Eg. more confident, more optimistic)

Is there anything else you'd like to tell us?

DIET

What did your child eat and drink yesterday?

FOOD	WHAT	QUANTITY	TEXTURE	UTENSIL
.1 Early morning				
.2 Mid morning				
.3 Midday				
.4 Afternoon				
.5 Evening/night				
DRINK				
.6 Over the whole day				

Are there other things your child typically eats & drinks but didn't eat yesterday? 1.Y 2.N 3.N/A

If yes, what things? _____

If sick yesterday: Did your child eat less because it was sick? 1.Y 2.N 3.N/A

In a typical day, how many times does this child eat? ☐

What food does s/he like? _____

dislike? _____

Note textures reported: Thin liquid ☐ Thick liquid ☐ Puree ☐
Soft solid ☐ Easy-to-bite solid ☐ Chewy solid ☐ Mixed consistency / lumpy ☐

Note utensils used: Hand ☐ Metal dessert spoon ☐ Chinese soup spoon ☐
Metal tsp ☐ Melamine tsp ☐ Feeder bottle ☐ Tall metal glass ☐ Short metal glass ☐
Tall plastic glass ☐ Short plastic glass ☐ Trainer cup ☐ Other_____ ☐

What food does your child usually eat in a month? (think of the past 3 months)

	Daily	Weekly	Monthly
1. Breast milk			
2. Cow's milk (besides in suji)			
3. Suji (RP/WP+milk+sugar)			
4. Suji (RP/WP+milk+oil+sug)			
(RP = rice powder) (WP= wheat powder)			

	D	W	M
5. Suji (RP/WP+oil+sugar)			
6. Suji (RP/WP+sugar alone)			
7. Kitchuri (own recipe) *			
8. Kitchuri (our recipe)			

	D	W	M
9.1 Normal rice			
9.2 Pulau rice			
10. Potato			
11. Green leafy vegetables			
12. Other vegetables			
13. Dhal / pulses			

	D	W	M
14. Fruits			
15. Banana			
16. Eggs			
17. Meat/poultry/fish M F			
18. Butter/cheese/yogurt			
19. Other:			

When cooking for this child, do you use extra oil? 1.Y 2.N

If Y: **Is this a new thing – since seeing us?** 1.Y 2.N 3. N/A

Is food availability for <u>this child</u> always 1. Poor 2. Reasonable 3. Varies during the year

If answer 3: **How has it been over the past 2 months?** 1. Poor 2. Reasonable 3. N/A

Has the family food changed over the past 2 months? 1.Y 2.N

If yes, in what way? _____

7

TEST OF KNOWLEDGE I want to ask you some general questions about food preparation and feeding:

Diet

1. **What is the most important cooking ingredient for giving your child energy ?**
   1. Oil
   2.Other

2. **How many times should you feed your child in a day?**
   1. Five or six
   2.Other:

3. **How much water should your child drink every day?**
   1. Five glasses
   2.Other:

Positioning & support for self-feeding

4. **In what position should you never feed your child?**
   1.Lying down / head back
   2.Other:

5. **Why?**
   1.Risks to chest
   2.Other:

6. **Why should you encourage your child to try to feed itself?**
   1.To encourage independence
   2. To make it want to eat
   3. Other:

Food consistency

7. **What food consistency should you avoid?**
   1.Mixed / very runny
   2.Other:

Responsive feeding

8. **How do you know what speed to feed your child and how much to put in his/her mouth?**
   1.Watch child's behaviour (or answer suggesting this)
   2.Other

9. **How should you encourage your child to eat?**
   1.Gentle and patient talking
   2. Other:

10. **Why should you not force your child to eat or drink?**
    1. It can be harmful to their chest
    2. It is cruel / unkind
    3. Other:

Hygiene

11. **Why should you only reheat food once?**
    1.Loses nutritional value
    2.Other:

12. **Why are worms not good for your child's health?**
    1.Child can't absorb goodness from food
    2.Other

TOTAL SCORE ☐

8

Appendix 15

Therapist Training Schedule

Therapist Training Schedule

Timetable (bold = formal teaching/supervision)

Sat-Wed (supervised by SLT)		Thurs – (unsupervised by SLT)	
8.30-9.30	**Group session**	**8.30-9.30**	Group session
9.30-10.00	**Observe snack time**	**9.30-10.00**	Observe snack time
10.00	BREAK	10.00	BREAK
10.30-12.00	**Teaching**	**10.30-12.00**	Observe/join in individual therapy
12.00-1.00	**Observe/manage lunch**	**12.00-1.00**	Observe/manage lunch
1.00	BREAK		
3.00-4.30	Observe/join in individual therapy		
4.30-6.00	**Teaching**		

		No of days
Week 1	(1-6 Nov)	
▪	Establish current level of knowledge, skills, feelings/attitudes	1
▪	Intro to CP and the feeding programme	1
▪	Intro to Mother & Child Unit	1
▪	Communication and interaction	2
Week 2	(8-13 Nov)	
▪	Communication contd	3
▪	Positioning (Mon & Wed)	2
Week 3	(15-20 Nov)	
▪	Feeding (ax and management) – NB. Digital camera > printing + laminating?	3
▪	Feeding and positioning (Mon & Wed)	2
	EID	
Week 4	(29 Nov-4 Dec)	
▪	Nutrition & Hygiene (ICDDRB)	5
Week5	(6-11 Dec)	
▪	Practical consolidation of Ax and management skills (all areas)	4
▪	Exam (c Sheila & Pauline)- Wed	1
Week 6	(13-18 Dec)	
▪	Transfer of skills - working together with supervision (Grp cooking session + indiv Ax, advice & training for 2+ mothers)	2
▪	Theory	3
Week 7	(20-25 Dec)	
▪	Consolidation - working with/without supervision	5
▪	Exam - Wed	1

Caregiver Training Sessions 1-6

Session 1

EDUCATIONAL PART

1. **Introduce the reason for the training sessions. (15-20 mins)**
   Why we are giving them training - the importance of feeding their children the best way possible:

   Feeding the wrong way =

   - Child is not eating enough nor nutritiously > (Malnutrition)
     Child is constantly feeling starved
     Child is underweight
     Child is not growing properly and not developing properly
     Child is unhealthy and at risk of disease and infection
     Child is irritable & unhappy

   - Child is not drinking enough > (Dehydration)
     Child is dehydrated
     Child is especially weak / floppy
     Child cannot concentrate
     Child is more especially constipated
     Child is irritable & unhappy
     Child can suffer organ damage and die

   The symptoms include a dry mouth, crying without tears, dry skin and little urination.

   - Food and drink go the wrong way> (Painful to swallow & Risk of pneumonia)
     Child experiences great distress and pain as food/drink hurts the lungs and child cannot breathe properly

     Child is at great risk of pneumonia caused by feeding the wrong way (= main cause of death in these children)

   Good feeding practices results in

   - Stopping these children from feeling hungry and miserable all the time > they are happy
   - Enabling proper nutrition > enables them to grow
     > makes them healthy and strong
     > allows them to develop to the best of their abilities
   - Reducing the risk of pneumonia
   - Reducing the stress / distress experienced by child (and mother) due to feeding being difficult

   Good feeders are

   Happy, patient, offer gentle verbal encouragement to eat, are sensitive and responsive to their child's needs.

1

2. Explain about the sessions: (10 mins)

- 6 sessions, every other week.
- Mums **must come to all** of them because they will learn different things on different days. If for any reason they cannot come on one day, then they should call us. They may be able to come on the next Sun / Thurs (depending which group) and join in with that group of mothers, to catch up. Fathers / other family members will be invited to the last session. However, if there is anyone else they think should be coming to every session, they must tell us.
- What they will learn:
  -What food to give the child
  -Special feeding techniques
- Structure of session:
  -Educational part - Discussion - Feeding practice
- Transport arrangements – discuss. NB. Taka for those who are not collected in minibus.
- They need to bring the food they normally feed the child, to each session.
- NB. They may have been prescribed drugs by doctor for GOR – it is important that they give them to their child. We will also be giving de-worming tablets. It is also essential that they give these to their child.

PRACTICAL SESSION

1. Explain about the chairs - Demonstration using doll (15 minutes)

- Why they are good for the children – to become more independent feeders and to help Mums to feed them more easily.
- Explain about putting cloth in first (protect from urine and reduce child's sweating). Then explain about padding around the pelvis and behind the head, using towels. Demonstrate.
- Tell them why the head position is so important (food / drink goes the wrong way).
- Then show how to tie the straps and emphasize low pelvic support.
- Put all the children in seats, if possible, and help Mums to get the right position using the padding. Put others in lap (forwards or sideways) and show Mums how to support appropriately.
- Explain we recommend the chair for feeding but also at other times of the day (4-5x 1/2hr – 1 hr each time), so child can watch what is happening, and so learn. It is also helpful for the mother as she can get on with her chores.
- Tell them the children will grow out of the chairs and the chairs may become damaged – especially if they get wet. So, they will need to come back to the Shishu and order another chair after some time. That time they will have to pay for them.

2. **Ask the Mums to get the food ready**. Go round and try to get the **right consistency** for each child by adding warm water (>more liquid) / cerelac (>more solid).

3. **Supervise the Mums feeding their children (30 mins)**

Show how to provide lip / jaw sport where necessary.
Tell them to keep their children upright / semi-upright for 30 mins after eating, to prevent vomiting.

WIND UP AND ARRANGEMENTS FOR NEXT WEEK

1. **Recap:** Why the training is important – dangers of malnutrition, dehydration, food / drink going the wrong way. Importance of happy mealtimes.

   Importance of the chairs & good positioning in them.

2. **Remind caregivers** of the day / date and time for next session. Remind all to bring food next time.

Materials

Food pictures and baskets

Cerelac – for cerelac vs water demo and for practical feeding session

Session 2

EDUCATIONAL PART

Revision

1. **Individually - Ask caregivers** how these 2 weeks went. Ask mums what they were able to do that we taught them. Anything they couldn't do? What? > Help them to think of a solution or tell them you will look at that during the practical feeding part of the session.

2. **Group discussion** - Ask the mothers/caregivers to tell you why we are teaching them about feeding their CP child.

   What do they remember about the chairs?

3. **Put the children to be put in chairs now, and give toys**

New teaching

FEEDING METHODS:

1. **Experiential activity – feeding methods**

   - Ask mothers/caregivers to:

     Get into pairs. 1 pair demonstrates then they all try:
     Put their partner into the breastfeeding position with their head back
     Give them a drink from a tall glass, quickly (but carefully!!)
     Give them biscuits very quickly and pushing it in.

   - Ask them to swap roles
   - Ask them how it felt to be fed. Did it hurt? Where?

2. **Go through the summary sheet**

   Point 6?: Positioning
   Point 7?: Support for the jaw and lips > try out on one another

DIET:

1. Diet activity

   - Put food pictures in middle of floor – (pumpkin, carrot, spinach, tomatoes, banana, papaya, oil, milk, meat, fish, eggs, dal, rice, potatoes, sugar, tea, soft drinks)
   - Ask mothers to divide them into <u>good</u> and <u>bad</u> piles.
   - Ask them to explain <u>why</u> things are good or bad.
   - Explain whether good / bad and why, and put into appropriate food category basket, or BAD basket!

3. Explain that these children need a **balanced diet** like all others but they also need food which has **more calories** in it as they cannot eat the same quantity of food at each mealtime as other children, because they get tired and start coughing. By adding extra oil, they get extra calories.

   For the same reason, they also need more frequent meals than other children. We recommend **6 meals a day**.

Spicy food is usually a problem for these children and is not recommended. Less salt is also good.

4. Tell Mums that the **consistency** of the food is also important for these children.
    - Show the orange, pineapple, nuts – explain why these are difficult.
    - Show the bowl of water vs bowl of cerelac and explain why the cerelac is easier for these children to swallow as it travels more slowly through the throat. Therefore be careful when you give **water**.
    - Make sure you don't mix consistencies – water and solid at the same time (eg biscuit & water, runny curry, hard rice and curry). This is very difficult to swallow. Kitchuri consistency is good.

5. Ask Mums what else do they also need to remember to give their children? (ie. **iodized salt**, **Vit A** tablets, **deworming syrup**). NB. Discuss where they can get iodized salt and Vit A.

6. Tell Mums children should have **5 glasses** of water a day. We know this is difficult to achieve, so aim for at least **3-4 glasses** a day. Give small amounts throughout the day. Not just at mealtimes!

7. Go through the diet sheet (whole group).

HYGIENE

Ask Mums:

- What they have to remember to do before feeding their child (wash hands and utensils with soap)
- How should they keep food after it is cooked and for how long (covered and fridge or left out for max ½ day)
- What else should they remember about body hygiene (keep nails short clean teeth, wash hands after toileting)

ENVIRONMENT

Go through summary sheet point 7:

"Feed your child in a clean place, and where it will not be distracted.
Your child needs to be in a clean place which is quiet and will not distract it from eating".

RECAP & ANY QUESTIONS

- Importance of good sitting position and head support
- Importance of nutritious food & a homogeneous consistency
- Importance of drinking enough
- Importance of a quiet, clean and safe environment for feeding.

PRACTICAL SESSION

1. Ask caregivers to get their children ready for feeding and start feeding.
2. Speak to each mother and help her carry out advice from individual goal sheets on feeding method.

WIND UP AND ARRANGEMENTS FOR NEXT WEEK

1. Remind caregivers of the day / date and time for next session. Remind all to bring food next time.
2. Remind all to try and follow what have learnt in training at home.

Materials
Diet charts & Teacup
Tall metal glasses
Large metal spoons
Biscuits

Session 3

EDUCATIONAL PART

Revision

1. **Ask how it went at home** – *individually*. What able to put into practice?
   What was difficult? Why? > solutions

2. **Revise what they learnt last time** – *group discussion*.
   Ask caregivers to tell you what they can remember from last time (NB. experiential session).
   Prompt them on the main points:
   -Positioning
   -Support for the jaw and lips
   -Diet
   -Hygiene
   -Environment

3. **Put the children in the chairs & give toys**

New teaching

1. **Go through summary sheet** 10,11, 12, 13,14?
   -Encouraging self-feeding
   -Correct utensils
   -Position of the spoon in spoon-feeding
   -Amount per mouthful and pacing

2. **Go through the Feeding Guidelines sheets** (blue)

3. **Add that they should prepare their child to eat** (see teaching summary point 5?):

   "All children should know that food is being prepared. Your children can watch you cooking and should see and smell the food before they eat it. If you do this, the child will be mentally prepared and so motivated to eat".

4. **Also add that they should feed in encouraging, responsive and sensitive way** (point 9?)

   "Talk to your child and have fun at mealtimes. Actively encourage your child to eat through gentle verbal encouragement. Do not be forceful in your words or actions. Watch your child's reactions and communications and feed them in a sensitive manner, in the way that they can manage. Never force feed. Stop feeding when the child indicates it is tired and has eaten enough."

   "Interaction and fun at mealtimes improve a child's emotional, cognitive, social, and communication development, and the mother-child relationship."

   "Active and sensitive feeding encourages the child to want to eat"
   "Research shows that children fed in all of these ways eat more and put on weight".

RECAP & QUESTIONS

- Encouraging self-feeding
- Correct utensils
- Position of the spoon in spoon-feeding

1

- Amount per mouthful and pacing
- Active, responsive and sensitive feeding

PRACTICAL SESSION

Supervised feeding session – refer to individual training needs (and amend these if necessary)

WIND UP AND ARRANGEMENTS FOR NEXT WEEK

1. Remind caregivers of the day / date and time for next session. Remind all to bring food next time.

2. Remind all to try and follow what have learnt in training at home.

Materials:

Feeding guidelines sheet

Session 4

EDUCATIONAL PART

Revision

1. **Ask how it went at home** - *individually*

   Discuss what able to put into practice. What was difficult? Why?
   Look for solutions with other mothers.

   Briefly check on: -Diet & consistency / Water intake
   -Hygiene
   -Positioning & use of chair (and use of chair at *other* times also)
   -Support for the jaw and lips
   Encouraging self-feeding
   -Correct utensils
   -Position of the spoon in spoon-feeding
   -Amount per mouthful and pacing

2. **Revise what they learnt last time** – *group discussion.*

   Ask mothers what they remember they were taught in the last session

   1. Encouraging self-feeding
   2. Correct utensils & position of spoon in mouth
   3. Prepare child for feeding & verbally encouraging it to eat during meal
   4. Being sensitive and responding to its signals (NB. Watch, notice, interpret, respond) including amount per mouthful and speed of feeding.

3. **Put the children in the chairs & give toys**

4. **Show videos** of other mothers - and ask these mums to watch out for:

   1. Positioning (+support for the jaw and lips)
   2. Encouraging self-feeding
   3. Verbal interaction & encouragement
   4. Sensitivity and responsiveness (eg. watching child's signals about correct amount per mouthful and pacing?)

   … and discuss

New teaching

Go through summary sheet

- Managing spillage (point 13)
- Clearing the mouth & teeth-cleaning (point 14)

RECAP & QUESTIONS

- Verbal interaction & encouragement
- Sensitivity and responsiveness
- Managing spillage (point 13?)
- Clearing the mouth & teeth-cleaning (point 14?)

SUPERVISED FEEDING SESSION

WIND UP AND ARRANGEMENTS FOR NEXT WEEK

1. Remind caregivers of the day / date and time for next session. Remind all to bring food next time.
2. Remind all to try and follow what have learnt in training at home.

Materials

Videos of other mothers

Session 5

1. **Ask how it has been going at home -** *individually*

   Discuss what they were able to put into practice. Was it helpful? What was difficult? Why? Look for solutions with other mothers

2. **Revise what they learnt in previous session –** *group discussion*

   - Managing spillage (point 13)
   - Clearing the mouth & teeth-cleaning (point 14)

3. **Put the children in the chairs & give toys.**

4. **Teach desensitization / alerting exercises & eating exercises & explain why they help**

   Desensitizing / alerting the child – to be done just before the child eats, at every mealtime.

   Put mothers into groups according to high or low tone.

   Demonstrate the massage techniques for each group:

   -Use the firm facial massage techniques for children with tight muscles
   -Use quick flicks / strokes for floppy children. Always make the movements in the direction of the mouth

   Mums try on each other (then their child).

   Explain why it is important

   Tongue exercises –

   Explain: Using the tooth brush – press down on middle of tongue and gently move it forwards and backwards along the tongue. Do the same on the sides of the tongue. Then push the tongue to one side and then the other.
   Be careful with sensitive children. Watch out for gagging and gradually build up child's tolerance of the activity.

   (Mums try with child).

   Explain: Encourage child to lick food from around the lips or lick lolly pops / honey, sugar or milk powder from palm of own / caregiver's hand.

   Why these exercises help with eating

   Chewing exercises –

   Explain: Use fruit wrapped in wet old saree material – place between teeth at the side of the mouth and support the chid to chew it with jaw support. *(Demonstrate with piece of saree material).*

   Help the child to mouth toys (clean!)

Give the child "bite to dissolve" foods and place them between the teeth at the side of the mouth. (Potato crackers, bisuit, but not normal chips. Note: these foods are not good for the diet but just for chewing practice).

Why these exercises help with eating

Lip exercises –

Explain: Help child to blow into whistles and party-blowers
Encourage your child to grip with its lips around the toothbrush or around a toy.

Why these exercises help with eating

RECAP & ANY QUESTIONS

5. **Supervised feeding session** (videoed)

6. **Wind up and arrangements for next week**

1. Take any outstanding photos
2. Remind caregivers of the day / date and time for next session & ask all to come early for chest reviews
3. Remind all to bring food next time and ask to bring fathers / mothers (absent caregivers)
4. Remind all to try and follow what have learnt in training at home.

Materials

Packet of Bombay crackers
Old saree material
Toothbrushes
"Flutes"

Session 6 (+ fathers/other caregiver)

1. **Welcome guests. Ask how it has been going at home.**

2. **Film** (40 mins)

   Tell the caregivers they will now see a film which we will talk about afterwards.
   After the film – ask mothers/caregivers what they thought of it. Why.

3. **Ask if they can remember the 5 main points of the training – go through the key phrases**

4. **Practical feeding** (short)

5. **General discussion about the whole training programme –**

Questions:

1. Overall, do you think the groups were helpful or not? Why yes, why no?....
2. What have you liked about coming to the groups?
3. What has been difficult about coming to the groups?
4. Will you be able to continue to do the new things you have learnt?
5. If not, which things will be difficult and why?
6. What would help you now that the groups are finishing? (eg to stay in touch with one another)
7. Do you have any suggestions for us when planning groups for mothers in the future?
8. Guests – do you have any comments about the training programme?

6. **Therapists explain more about the service at the Shishu and why it is helpful for disabled children.**

7. **Wind up**

Discuss any follow-up arangements

Materials
Video drama

Appendix 17

Advice sheet: feeding practices

Advice sheet: recipes for kichuri and suji

রেসিপি

খিচুড়ী	দুধ সুজি
ভাত 	গুড়া দুধ 
ডাল 	চালের গুড়া 
শব্জি (মিষ্টি কুমড়া এবং শাক) 	চিনি
তেল 	তেল 
পেঁয়াজ 	পানি 
হলুদ	
অল্প পরিমাণে লবণ 	
পানি 	
সম্ভব হলে মাছ 	

ক্রিমির ঔষধ (এ্যালবেন)

১-২ বছর ১ চা-চামচ ১ ডোজ প্রতি ৩ মাসে একবার

২+ বছর ২ চা-চামচ ১ ডোজ প্রতি ৩ মাসে একবার

Advice sheet: daily dietary chart

বয়স ১ বছর

১	২	৩	৪	৫	৬
দুধ (¾ কাপ) ও ½টি ছোট কলা	দুধ সুজি (১৫০ মিলি)+১ চা চামচ তেল	খিচুড়ী (১কাপ) + ২ চা চামচ তেল	দুধ সুজি (১৫০ মিলি)+১ চা চামচ তেল	খিচুড়ী (১কাপ)+ ২ চা চামচ তেল	দুধ সুজি (১৫০ মিলি) + ১ চা চামচ তেল
	ডিম (১)				

বয়স ২-৩ বছর

১	২	৩	৪	৫	৬
দুধ (¾ কাপ) ও ১টি ছোট কলা	দুধ সুজি (২২৫ মিলি)+½ চা চামচ তেল	খিচুড়ী (১ ½কাপ) + ৩½ চা চামচ তেল	দুধ সুজি (২২৫ মিলি)+ ½ চা চামচ তেল	খিচুড়ী (১½কাপ)+ ৩½ চা চামচ তেল	দুধ সুজি (২২৫ মিলি) + ½চা চামচ তেল
	ডিম (১)				

বয়স ৪-৬ বছর

১	২	৩	৪	৫	৬
দুধ (১½ কাপ) +১½টি ছোট কলা	দুধ সুজি (২৬০মিলি)+ ½ চা চামচ তেল	খিচুড়ী (২কাপ) + ৭ চা চামচ তেল	দুধ সুজি (২৬০ মিলি)+ ½চা চামচ তেল	খিচুড়ী (২কাপ)+ ৭ চা চামচ তেল	দুধ সুজি (২৬০ মিলি) + ½চা চামচ তেল
	ডিম (১)				

বয়স ৭-৯ বছর

১	২	৩	৪	৫	৬
দুধ (২ কাপ) +১½টি ছোট কলা	দুধ সুজি (২৬০ মিলি)+½ চা চামচ তেল	খিচুড়ী (৩ কাপ) + ৭ চা চামচ তেল	দুধ সুজি (২৬০মিলি)+½ চা চামচ তেল	খিচুড়ী (৩ কাপ)+ ৭ চা চামচ তেল	দুধ সুজি (২৬০ মিলি) + ½ চা চামচ তেল
	ডিম (১)				

Appendix 20

Reliability scores FORM 7

The results of pre-and post-study reliability-testing of FORM 7 are summarised in the table below, grouped according to the agreement categories of Fleiss (1981). Abbreviations are used for food *(F)* and drink *(D)*.

Level of agreement during pre and post-study retrospective reliability-testing (FORM 7)

Variable	**Agreement score Cohen's Kappa** *n*=15
	<0.40
Responsiveness	0.16
Negative verbal proactiveness	0.27
	0.40-0.60 (fair)
Child affect	0.55 (post-study testing: 0.71)
Amount per mouthful (D)	0.58
Positive verbal proactiveness	0.59
	0.60-0.75 (good)
Negative physical proactiveness	0.61
Amount per mouthful (F)	0.68
Pacing (F)	0.71
Support for lips/jaw (D)	0.75
	>0.75 (excellent)
Head position – degree of extension (D)	0.77
Pacing (D)	0.84
Head position – degree of extension (F)	0.85
Trunk position (F)	0.88
Utensil (F)	0.90
Utensil (D)	0.94
Trunk position (D)	0.92
Support for lips/jaw (F)	1.00
Support for self-feeding (F&D)	1.00

Methods of Statistical Analysis

The table below summarises the data analyses. The method of data was collection is also noted. Methods include objective measurements (OM), researcher observations (O), caregiver reports (R) or a combination of observations and reports (O+R).

Summary of variables and their methods of analysis

Variables	Statistical & Descriptive	Statistical Tests Used	Descriptive
Child outcomes			
Nutritional Status	▪ WAZ, MUAC/Z, BMIZ. (OM)	ANOVA / Paired Samples T-test	
Chest Health	▪ Signs of aspiration (O & R) ▪ Frequency of chest-related illness (R)	Friedman / Wilcoxon	▪ Signs of aspiration - frequency of coughing (R)
Levels of child discomfort & distress during feeding	▪ Signs of discomfort/distress (O & R) ▪ Fussiness (R) ▪ Food refusal (R)	Friedman / Wilcoxon	▪ Crying during feeding (R) ▪ Fussiness (R) ▪ Food refusal (R)
Child Feeding Skills	▪ Maturity of oral feeding manner (O)	Friedman / Wilcoxon	▪ Oral spillage (R)
	▪ Degree of oral spillage (O) ▪ Degree of oral spillage (R)	Cochran / McNemar Friedman / Wilcoxon	
	▪ Involvement in self-feeding (O)	Friedman / Wilcoxon	
Additional benefits to the child	▪ General mood (R)	Friedman / Wilcoxon	▪ General health (R)
Caregiver outcomes			
Psychological impact	▪ Stress regarding feeding (R)	Friedman / Wilcoxon	
Burden of care	▪ Time taken for feeding (R)		
Feeding practices			
Ensuring adequate nutrition and fluid intake	▪ Diet (R)	Friedman / Wilcoxon	▪ Adding oil to food (R) ▪ Frequency of meals (R) ▪ Quantity of food intake (R)
	▪ Responding to hunger (R)	Cochran / McNemar	
	▪ Giving enough drinks (R)	Friedman / Wilcoxon	
	▪ Positive verbal proactiveness (O)	Friedman / Wilcoxon	
Minimising risks to chest health	▪ Positioning (O)	Friedman / Wilcoxon	
	▪ Use of adapted seat (O)	Cochran / McNemar	
	▪ Food consistency (O)	Cochran / McNemar	
	▪ Homogeneity (O)		
	▪ Utensil (O)		
	▪ Sensitivity to cues (R)	Friedman / Wilcoxon	
	▪ Responsiveness of feeding manner (O)		
	▪ Minimising negative interaction & forcing (R+O)		
Overall level of appropriateness of feeding practices	▪ Number of aims identified ▪ Number of targets identified	ANOVA / Paired Samples T-test	
	▪ Appropriateness of feeding ('compliance' scores)	Friedman / Wilcoxon	

Comparison of C1 and C2 data

CHILDREN

Mean WAZ(British 1990)

		BSL	PTR1	PTR2
C1	*n* 11	-4.83	-4.83	-4.75
	SD	*1.93*	*2.21*	*2.52*
C2		-4.84	-4.97	-3.46
	SD	*1.85*	*2.09*	*2.33*

Mean WAZ(CP 2006)

		BSL	PTR1	PTR2
C1	*n* 8	-3.10	-2.76	-2.36
	SD	*1.10*	*2.84*	*2.01*
C2	*n* 10	-2.86	-2.33	-2.29
	SD	*1.93*	*1.32*	*1.27*

Mean MUAC (cm)

		BSL	PTR1	PTR2
C1	*n* 11	**14.71**	**14.85**	**15.25**
	Std dev	*1.50*	*1.95*	*1.86*
C2		**14.79**	**15.21**	**15.65**
	Std dev	*1.38*	*1.74*	*1.32*

Mean MUACZ(CP 2006)

		BSL	PTR1	PTR2
C1	*n* 8	**-0.40**	**-0.46**	**-0.47**
	Std dev	*0.53*	*0.84*	*0.84*
C2	*n* 10	**-0.44**	**-0.42**	**-0.29**
	Std dev	*0.64*	*0.86*	*0.54*

Mean BMIZ(British 1990)

		BSL	PTR1	PTR2
C1		**-4.58**	**-5.63**	**-3.69**
	Std dev	*3.54*	*6.60*	*3.94*
C2		**-3.62**	**-3.47**	**-2.81**
	Std dev	*2.13*	*2.04*	*1.80*

Mean number of frequently observed pharyngeal signs (food & drink combined)

Advice plus training		BSL	PTR1	PTR2
C1	**Mean**	**3.6**	**0.9**	**1.0**
	Std. dev	*3.72*	*1.37*	*1.89*
C2	**Mean**	**1.2**	**0.9**	**0.5**
	Std. dev	*1.95*	*0.90*	*0.91*

Mean score of reported coughing (Maximum potential score of 4)

	BSL	PTR1	PTR2
C1	**2.7**	**1.7**	**1.0**
Std dev	*1.42*	*1.25*	*1.25*
C2	**2.3**	**1.3**	**1.0**
Std dev	*0.87*	*1.30*	*1.13*

Mean score of chest-related illness

	BSL	PTR1	PTR2
C1	1.2	1.1	0.6
SD	*1.03*	*1.20*	*0.84*
C2	1.2	0.3	0.3
SD	*1.02*	*0.49*	*0.65*

Mean score of observed discomfort/distress

	BSL	PTR1	PTR2
C1	2.5	0.2	0.6
SD	*2.51*	*0.42*	*1.27*
C2	1.3	0.5	1.0
SD	*1.78*	*0.91*	*1.21*

Mean score of crying (Maximum potential score of 3)

	BSL	PTR1	PTR2
C1	1.0	0.5	0.2
SD	*0.94*	*0.71*	*0.42*
C2	0.9	0.3	0.3
SD	*0.79*	*0.45*	*0.49*

Percentage of children reported to be fussy about their food

	BSL	PTR1	PTR2
C1	60	40	20
C2	67	25	33

Mean score of food refusal (Maximum potential score of 3)

	BSL	PTR1	PTR2
C1	1.4	0.7	0.7
SD	*0.52*	*0.48*	*0.48*
C2	1.3	0.7	0.8
SD	*0.65*	*0.65*	*0.58*

Percentage of children observed at different stages of feeding maturity

	BSL					PTR1					PTR2				
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
C1	20	50	30	0	0	0	40	50	10	0	0	10	60	30	0
C2	25	50	17	0	8	0	25	25	33	17	0	25	33	8	33

Mean score of maturity of oral feeding

	BSL	PTR1	PTR2
C1	2.1	2.7	3.2
SD	*0.74*	*0.68*	*0.63*
C2	2.2	3.4	3.5
SD	*1.12*	*1.08*	*1.24*

Percentage of children displaying marked oral spillage during feeding

	BSL	PTR1	PTR2
C1	100	90	70
C2	83	50	64

Mean score of reported oral spillage

	BSL	PTR1	PTR2
C1	1.3	1.1	0.9
SD	*0.95*	*0.88*	*0.99*
C2	1.7	0.7	0.9
SD	*0.65*	*0.89*	*0.79*

Mean score of self-feeding (maximum 2 points)

	BSL	PTR1	PTR2
C1	**0**	**0.2**	**0.2**
SD	*0.00*	*0.42*	*0.42*
C2	**0**	**0.3**	**0.4**
SD	*0.00*	*0.65*	*0.80*

Mean rating of 'positivity'

	BSL	PTR1	PTR2
C1	**0.0**	**1.7**	**1.7**
SD	*0.00*	*0.68*	*0.68*
C2	**1.2**	**1.8**	**1.8**
SD	*1.03*	*0.58*	*0.58*

CAREGIVERS

Mean level of feeding-related stress reported by caregivers

	BSL	PTR1	PTR2
C1	**2.8**	**0.7**	**0.8**
SD	*0.42*	*1.25*	*1.03*
C2	**2.8**	**1.9**	**0.6**
SD	*0.39*	*1.44*	*1.00*

Mean length of assessed mealtime (in minutes)

	BSL	PTR1	PTR2
C1 (*n*=7)	11.9	21.4	25.7
SD	*3.02*	*12.49*	*8.86*
C2 (*n*=9)	8.9	22.4	18.6
SD	*3.26*	*10.25*	*9.02*

Percentage average meal length (reported)

	BSL			PTR1			PTR2		
	<30 mins	30-60 mins	>60 mins	<30 mins	30-60 mins	>60 mins	<30 mins	30-60 mins	>60 mins
C1	20	80	0	20	80	0	50	50	0
C2	17	83	0	33	67	0	58	42	0

TRAINING

Mean number of times each food type eaten per day (The shading is used to aid reading of the table)

	BSL				PTR1				PTR2			
	V	P	F	M	V	P	F	M	V	P	F	M
C1	1.2	1.5	1.1	2.4	2.4	2.6	1.1	2.6	1.0	1.5	1.7	2.9
SD	*1.14*	*1.14*	*1.31*	*1.88*	*1.93*	*1.11*	*0.83*	*1.88*	*0.97*	*1.18*	*1.86*	*1.34*
C2	1.1	1.5	0.8	3.7	2.0	2.0	1.3	2.8	2.0	2.4	0.8	2.3
SD	*1.60*	*1.72*	*1.12*	*2.01*	*1.86*	*1.32*	*1.62*	*2.24*	*2.02*	*1.81*	*1.02*	*2.42*

Percentage of caregivers reportedly giving extra oil as a result of training

	PTR1	PTR2
C1	90	40
C2	67	75

Percentage of children for whom food availability was reported as an issue in the previous month

	BSL	PTR1	PTR2
C1	0%	30%	40%
C2	25%	42%	25%

Mean number of meals given per day

	BSL	PTR1	PTR2
C1	4.9	5.2	4.9
SD	*1.45*	*1.62*	*1.85*
C2	5.3	5.7	5.4
SD	*1.61*	*1.50*	*1.38*

Percentage of caregivers who fed their child at signs of hunger

	BSL	PTR1	PTR2
C1	50	60	90
C2	50	100	75

Mean food intake in ml

	BSL	PTR1	PTR2
C1	742.1	1044.7	750.5
Min-Max	265-1550	530-1600	165-1345
SD	*381.36*	*392.41*	*361.72*
C2 (*n*=9)	908.9	787.2	1025.6
Min-Max	245-1575	375-1100	105-1700
SD	*451.36*	*265.3*	*461.1*

Approximate mean fluid intake through drinks (ml)

	BSL	PTR1	PTR2
C1	159.8	397.0	296.5
Min-Max	0-375	250-850	20-595
SD	*122.53*	*186.00*	*159.22*
C2 (*n*=9)	188.4	330.0	303.6
Min-Max	50-310	25-650	35-1000
SD	*96.02*	*203.67*	*269.25*

Mean positive verbal proactiveness

	BSL	PTR1	PTR2
C1 (*n*=9)	0.9	2.7	1.8
SD	*0.93*	*1.23*	*1.48*
C2	1.2	3.3	3.0
SD	*1.47*	*1.06*	*1.21*

Percentage of children observed in each position at some point during the assessed mealtime

	BSL		PTR1		PTR2	
	Lying/ Breast-feeding	45° /upright	Lying/ Breast-feeding	45° /upright	Lying/ Breast-feeding	45° /upright
C1						
Food	100	10	0	100	10	100
Drink	100	10	20	100	30	100
C2						
Food	58	42	8	100	17	100
Drink	67	33	0	100	8	100

Percentage of children observed in each position at any time during the assessed mealtimes

	BSL		PTR1		PTR2	
	Extended	Straight / flexed	Extended	Straight / flexed	Extended	Straight / flexed
C1						
F	100	30	100	60	80	60
D	100	0	10	50	90	20
C2						
F	100	42	92	50	92	75
D	100	33	25	42	75	58

Percentage use of adapted seat for feeding (observed)

	BSL		PTR1		PTR2	
	F	D	F	D	F	D
C1	0	0	40	20	20	20
C2	0	0	42	33	8	8

Percentage of children observed eating foods in each category at any point in the assessment

	Thick liquid			Puree			Soft-solid		
	BSL	PTR1	PTR2	BSL	PTR1	PTR2	BSL	PTR1	PTR2
C1	20	0	0	50	40	20	30	60	80
C2	36	0	0	55	27	46	9	73	55

Percentage of food observed to be homogenous

	BSL	PTR1	PTR2
C1	40	70	50
C2	73	82	64

Percentage usage of inappropriate utensil

	BSL	PTR1	PTR2
C1	**38**	**4**	**10**
C2	**31**	**4**	**8**

Mean score of sensitivity (maximum potential sore of 9)

	BSL	PTR1	PTR2
C1	**3.8**	**5.3**	
SD	*1.03*	*1.34*	
C2	**3.8**	**5.4**	
SD	*1.55*	*1.44*	

Mean responsiveness of feeding manner (maximum potential score of 4)

	BSL	PTR1	PTR2
C1	0.7	2.4	3.0
SD	*0.48*	*0.84*	*0.94*
C2 n=11	1.8	2.5	2.8
SD	*1.08*	*0.69*	*1.08*

Mean negative verbal proactiveness (maximum potential total score of 6)

	BSL	PTR1	PTR2
C1	1.3	1.2	1.1
SD	*0.95*	*1.14*	*1.29*
C2	0.9	0.8	0.6
SD	*0.52*	*0.29*	*0.90*

Mean negative physical proactiveness (maximum potential score of 6)

	BSL	PTR1	PTR2
C1	3.2	0.5	0.6
SD	*1.69*	*0.71*	*0.70*
C2	1.5	0.1	0.7
SD	*1.17*	*0.29*	*0.99*

Mean number of aims identified

	BSL	PTR1	PTR2
C1 (N=9)	8.2	5.0	5.7
SD	*1.56*	*1.87*	*1.73*
C2 (N=11)	7.5	4.5	4.6
SD	*2.73*	*2.02*	*1.75*

Mean number of training areas identified

	BSL	PTR1	PTR2
C1 (N=9)	18.7	9.9	10.4
SD	*1.23*	*3.10*	*1.88*
C2	16.4	6.9	7.1
SD	*3.26*	*3.42*	*2.68*

Mean percentage attainment of 'appropriate feeding'

	BSL	PTR1	PTR2
C1	**0.0**	**61.7**	**57.0**
SD	*0.00*	*9.46*	*9.59*
C2	**0.0**	**71.0**	**70.6**
SD	*0.00*	*13.75*	*12.51*